DOCUMENT RESUME

ED 285 379 EC 200 468

AUTHOR Biro, Patricia; And Others
TITLE High Priority Infant Tracking Project. Final Report.
INSTITUTION Washington State Dept. of Social and Health Services, Olympia. Div. of Health.; Washington Univ., Seattle. Child Development and Mental Retardation Center.
SPONS AGENCY Health Resources and Services Administration, Rockville, MD. Bureau of Health Care Delivery and Assistance.
PUB DATE Jun 86
GRANT MCJ-533045
NOTE 262p.
PUB TYPE Reports - Evaluative/Feasibility (142) -- Information Analyses (070)

EDRS PRICE MF01/PC11 Plus Postage.
DESCRIPTORS Developmental Disabilities; *Disabilities; *Health Services; *High Risk Persons; Identification; Infants; *Maintenance; Prediction; Screening Tests; State Programs
IDENTIFIERS *Washington

ABSTRACT

The study compared the effectiveness of the Washington State High Priority Infant Tracking Project in maintaining high risk infants in continuing health care, determining health and developmental outcomes, and surveying the use of community resources with other state tracking projects. The project identifies infants during the first 30 days of life according to 17 criteria incorporating medical, social, and environmental risk factors. Data is collected on infants at 3, 6, 18, 24, and 36 months of age via a questionnaire administered to the primary care provider. More than 85% of the high priority infants identified and enrolled have been maintained in ongoing health care and developmental surveillance. The largest groups of high priority infants had low birthweights. Medical problems identified at 3 and 6 months were predictive of later medical problems. Developmental problems identified at 6 months were predictive of later developmental problems. A significant relationship between early health problems and later developmental problems was identified. The overall incidence of health problems in the sample population was 40% and of developmental problems was 20%. A literature review demonstrating the need for such a tracking program precedes the study. Project evaluation results, minutes of a State Advisory Committee meeting at which the project was reviewed, and a transcript of the project procedures manual conclude the document. (DB)

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ED285379

Washington State HIGH PRIORITY INFANT TRACKING PROGRAM

FINAL REPORT OF PROJECT supported by Grant Number MCJ-533045
Bureau of Health Care Delivery and Assistance,
Department of Health and Human Services

OCTOBER 1982 through JUNE 1986

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Child Development and Mental Retardation Center
University of Washington
Seattle, WA 98195

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HIGH PRIORITY INFANT TRACKING PROJECT

Principal Investigator: Clifford J. Sells, M.D.

Co-Investigators: Patricia Biro, M.Ed.
Deborah Padgett, M.S.N., P.N.P.
Melinda Knutson, P.N.P., M.P.H.
Mary Hammond, Ph.D.
Marilyn Bergner, Ph.D.
Michelle A. Bell, Ph.D.

Tracking Portion of the Final Report of Projects Supported by Grant Number MCJ-533045, Bureau of Health Care Delivery and Assistance.

October 1982 through March 1986

EC 200468

Washington State Office of Parent Child Health Services in cooperation with the University of Washington, Child Development and Mental Retardation Center, Seattle, Washington 98195.

WASHINGTON STATE HIGH PRIORITY INFANT TRACKING PROJECT

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ACKNOWLEDGEMENTS

Special thanks goes to all those individuals whose time, creativity, and commitment have been devoted to this project since its inception.

State Advisory Committee

Susan Baxter
Harry Carthum
Jan Dahl
Kathleen Eussen
Bobbie Evans
Duryln Finnie
Joan Gaetz
Todd Gay
Jeffrey Graham
Karen Holt
Marty Jacobs
Peter Johnson
Jean Kajikawa
Jeff McLaughlin
John Moyer
Mary O'Mara
Barbara O'Neill
Robert Scherz
Nancy Smith
Donald Sutherland
John G. Vornbrock
Steven Wisner

Tertiary Care Centers

Sally Baque
Jayne Freitag-Koontz
Pat Harnish
Carol Heines
Pat Rutledge
Peggy West
Elaine Zech

Thurston County

Mary Allen
Aleta Jesperson
Laura Davidson
Henry deGive
Arleta Erickson
Kathleen Eussen
Carol Herr
Karen Holt
Jim King
Christine Nelson

Thurston County (Cont.)

Janet Shefferly
Barbara Zebbs
Thurston County Advisory Board Members
Participating Thurston County Physicians

Whatcom County

Helen Crandall
Jan Dahl
Jan Halsey
Theresa Westerburg
Diane Wilson
Steve Wisner
Whatcom County Advisory Board Members
Participating Whatcom County Physicians

University of Washington

Michelle Bell
Marilyn Bergner
Patricia Biro
Patricia Brandt
Mary Hammond
Connie Nakao
Deborah Padgett
Bill Sciarillo
Clifford Sells
Carol Weiss
Forrest Bennett

Office of Parent-Child Health Services (DSHS)

Kathy Chapman
Melinda Knutson
Fran Moellman
Peter Pulrang
Patricia Wilkins
Judith Maire (now with Office of the Superintendent of Public Instruction)

INTRODUCTION

From October 1982 to the present, Washington State developed and established a system for identifying and tracking high risk infants from birth to age three years. This project is an exciting one and has produced new knowledge about the benefits and difficulties of establishing a tracking system. We examined national research, statewide and local level issues as well as procedural and technical content of a tracking program.

Our efforts demonstrate that it is possible to identify and track high risk infants in a cost-effective manner. It is possible to provide this as an integrated service of the community health care system, including hospitals, health departments, and primary care providers. Educators and social services providers need to be involved in the planning of a tracking system as well. Identification and tracking are the first steps in the development of comprehensive services for at risk infants and children. Without such a system as a foundation, intervention services cannot be provided in a timely and maximally preventive manner.

Washington State continues to support the concept of statewide tracking. We hope that the information contained herein will prove valuable to other states currently involved with or seeking to institute tracking systems. We actively solicit ideas or information which would help to improve our program.

Melinda Knutson, R.N., M.P.H., P.N.P.
Public Health Nursing Consultant
Parent-Child Health Services LC-12A
Olympia, Washington 98504
(206) 586-6721
July 10, 1986

TRACKING INFANTS AT RISK

Review of the Literature

Analysis of United States Tracking Systems/Comparison with Washington State

Recommendations for Program Improvement

Melinda Knutson, R.N., P.N.P., M.P.H.
Public Health Nurse Consultant
Washington State Office of Parent and Child Health

April 1986

INTRODUCTION

Early identification of infants and children with health or developmental disability has been addressed in a variety of ways by states and communities. The problem is one of balancing the cost of the identification method with the benefit gained from the earliest possible identification. The goal is to find children with problems as early as possible so that their disability can be minimized and their development maximized. This means preparing them to optimize their school experience and, ultimately, to become productive members of society.

Recent improvements in neonatal intensive care have reduced the numbers of low birthweight and premature infants who die in the neonatal period. Research is showing these children are at risk for health or developmental problems because of the difficulties they experienced in the neonatal period (Bennett). Children who live in homes which are disruptive, whose parents are very young, mentally ill, or abuse alcohol or drugs have also been shown to have developmental problems (Cohen, Siegel).

In 1982, the Office of Maternal and Child Health Services, Washington State Department of Social and Health Services, recognized the need to develop a system that would provide early identification of infants and children with health or developmental problems, assist their parents in maintaining ongoing health supervision for them from their primary health care provider, and help the state to adequately plan for the needs of these children both in terms of health care and educational resources. Thus, the High Priority Infant Tracking (HPIT) program was born, modeled after a similar program in North Carolina. Currently in two pilot counties, the program involves the entire health care community, including the hospitals, the private medical care providers, and the public health department.

This paper is an investigation into research surrounding the high risk infant and child and available methods for early identification of children with disabilities. The Washington State High Priority Infant Tracking Project is compared with other state tracking projects. Its effectiveness in meeting the needs of the children it serves is evaluated.

LITERATURE REVIEW

It is well established that infants experiencing a variety of prenatal, perinatal, and neonatal insults are at higher risk of developmental delay, major and minor neurological impairment, and school learning difficulties. Prediction of which infants with which risk factors will experience problems is not well defined at the present time. Much research is ongoing to identify which risk facors are predictive of developmental, neurological, and educational disability.

Infants at risk for disability can be categorized into three groups:

1. Established risk - Infants with known chromosomal, structural, or metabolic defects. These infants can usually be identified in the perinatal period and referred for further evaluation and early intervention services.

2. Biological risk - Infants with a potential for neurodevelopmental or educational disability due to a history of prenatal, perinatal, or neonatal insult. These infants can be identified in the neonatal period by health care providers. Actual disabilities can be detected by periodic physical and neurodevelopmental evaluation from infancy through school age.

3. Environmental risk - Infants with potential for delayed development due to social or family stresses. Examples of this include adolescent parenting, developmental delay of the parent, low socioeconomic status, and a history of drug or child abuse in the family. Many of these infants can be identified in the neonatal period by health care providers if these factors are included in the data collection process. Ongoing evaluation of the impact of this risk factor can be assessed by health care providers providing follow-up services to these families and infants. Actual disability can be detected by periodic pnysical, neurodevelopmental, psychosocial, and educational evaluation. (Tjossem, 1976; Ramey and Trohanis, 1982; National Project 0-3 Survey Report, 1985)

Established Risk

Infants born who are at established risk, (any handicapping condition such as Down syndrome, meningomyelocele, cystic fibrosis or malformation) are known to experience developmental and learning problems. These problems can be due to the direct effect on the nervous system from the condition itself, as in Down syndrome and meningomyelocele.

Developmental problems can also result from the stress the condition places on the child and family's coping skills which may delay the achievement of normal developmental milestones. Children with established risk clearly have special needs which can be identified. Early intervention is effective in ameliorating the effects of these conditions.

Over 1,100 infants (2 percent of all births) were born in Washington State in 1984 who were at established risk for developmental and learning problems.

Biological Risk

Many biological risk factors also have a strong correlation with neurodevelopmental and educational disability. In 1984 there were approximately 5,800 infants born in Washington State who were at biological risk for developmental and learning problems (8% of all births). A literature review by Bennett (1984) of the last 20 years of research conducted in the United States, Canada, United Kingdom, Australia, Scandinavia and Switzerland reveals the following findings for infants at biological risk for neurodevelopmental disability.

Major handicapping conditions have long been recognized to be associated with low birthweight (less than 2500 grams) and complications surrounding birth. The rate of incidence of these conditions in low birthweight infants is about 20 percent. Included are cerebral palsy, mental or developmental retardation, sensorineural hearing loss, and visual impairment.

"With careful developmental screening and repeated neuromotor examination of all NICU graduates, most of these major handicaps are identified and intervention is started by one year of age; all major handicaps should be detected before age three." (Bennett, 1984, page 6)

A new classification of disability, termed the "minor" handicapping conditions has been described and is stimulating increasing interest from researchers and clinicians. Minor handicapping conditions are more difficult to diagnose early, and may be detected first at school age when the child presents with learning difficulties.

Minor handicapping conditions include borderline intelligence (IQ scores 70-84), neuromotor abnormalities, communication disorders, and learning disabilities. Such problems are estimated to be at least as prevalent as the major disorders. In very low birthweight infants (less than 1500 grams), the incidence is about 15-25 percent. These statistics in combination with the rate for major handicapping conditions leads to an estimate of 35-45 percent of very low birthweight infants with major and minor neurodevelopmental problems. (Bennett, 1984)

Abnormal neuromotor signs on physical examination in the first year of life termed "transient dystonia" have been shown to be predictive of language, learning, and behavioral problems (minimal brain dysfunction). About 60 percent of very low birthweight infants have transient dystonia. By nine months corrected age, most of these infants who do not have cerebral palsy have a normal physical examination, but may present later with a minor handicapping condition. Low birthweight infants perform less well than normal birth weight infants on the Brazelton Neonatal Behavioral Scale. Temperamental differences have also been shown, with low birthweight infants more often categorized as "difficult" with low adaptability to change, more negative mood, and greater distractability than normal weight infants. (Bennett, 1984). Premature infants have been shown to be significantly less responsive to their parents, less alert, and have more disorganized sleep and . . ing cycles than full term infants. (Telzrow, et al, 1982)

School performance of low birthweight infants is be affected. A prevalence rate of 42 percent (all degrees of handicap) in children who were low birthweight has been reported at early school age. Problems include language disorders, reading disability, hyperactivity, clumsiness, perceptual functioning and decreased mathematics ability. Long-term problems such as difficulty with verbal expression, academic achievement, social relationships, and emotional maturity not attributable to socioeconomic or parenting differences have been found at 8-15 years of age. (Bennett, 1984, Klein, et al., 1985)

Infants who are low birthweight and have other risk factors are at even greater risk of neurodevelopmental problems. Infants small for gestational age (SGA) have been shown to be at greater risk than infants average for gestational age (AGA). Handicap rates have been estimated at 30-50 percent for infants both premature and SGA. (Bennett, 1984; Cohen, 1983; Dunn, 1980)

Studies have shown that infants with seizures, hypotonia, and CNS infections have higher rates of referral for developmental problems. Infants with CNS infections have significant sequelae with only about 25 percent developmentally normal at preschool. (Blackman, 1985; Bennett, 1984)

Several researchers have found neurological assessment of the infant either in the neonatal period or at 4 months of age to be significantly related to measures of handicapping at older ages. (Harris, 1984, Robertson, 1985, Bierman-van Eendenburg, 1981) Harris is presently in the process of refining which parts of the neurological assessment are most predictive. (Harris, in press) Her research is beginning to show the best assessment is made by observing the infant's movement against gravity rather than handling and stimulation during the assessment. Other research is showing that infant behavioral assessment (usually assessed with the Brazelton Scale) can be predictive of later neurological and developmental status. (Sell, et al., 1985)

The above efforts demonstrate that research is continuing to attempt to predict as accurately as possible which infants are at risk for later

negative neurological or developmental outcomes. The fact remains that infants with similar biologic risk factors display wide diversity of outcomes in terms of intelligence and social functioning. (Siegel, 1985) It is generally believed that environmental factors are largely responsible for this diversity.

Environmental Risk

The environment the infant is born into and matures within plays a large role in the ultimate development and intellectual functioning of that child. Socioeconomic status has been shown to have an even greater effect on the development and school functioning of an individual child than the biological risk factors [except for very low birthweight (VLBW)]. (Cohen, 1983) It is not known how many infants are born at environmental risk each year in Washington State.

Betty Caldwell and colleagues have shown that homes which have a positive environment (access to stimulating play materials, allowance of exploration on the part of the child, modulated amounts and varieties of sensory experience and a positive emotional climate) are correlated with positive outcomes on intelligence scores at later ages. The HOME (Home Observation for Measurement of the Environment) scale has been developed to measure this environment and has been used in much of the research done in this area. (Bradley and Caldwell, 1977)

Longitudinal research at the University of Washington School of Nursing (Eyres, et al, 1979 and Hammond, et al, 1983) has shown the critical importance of the child's environment in predicting later cognitive and emotional functioning. A cohort of children were followed from birth to age four. The findings at the four-year evaluation showed that the family milieu which included such things as the degree of support available to the mother, the inanimate enrichment of the environment (toys and play materials, opportunities for stimulation), and the mother's typical mode of response to the child (loving and supportive as opposed to hostile and restrictive) were predictive of later intellectual and emotional functioning. (Eyres,

et al, 1979) The same children were evaluated at second grade. The results found at age four were largely confirmed. Furthermore, they found that a child's school performance and cognitive functioning can be about equally predicted from assessments of the child's environment or from assessment of the child's own earlier functioning. (Hammond, et al, 1983) The aspect of the child's environment called "family ecology" was further explored. Family ecology is that part of the child's environment that includes such things as life change and social support available to the parents. This aspect of the environment was found to be predictive of later child functioning. Learning problems were predicted by the combination of biological risk factors and environmental risk factors. Behavior problems were predicted by a combination of early language development, slow motor development, and family disruption.

Interesting findings regarding the mother's functioning were discussed in the Hammond (1983) study. HOME scores were highly correlated with cognitive outcomes for children of low education mothers, while scores of the teaching skills of mothers with high education correlated with their offsprings' cognitive outcomes. The authors speculate that there may be a threshold of adequacy of the home environment which must be met before teaching skills significantly affect learning. It also appeared that well educated mothers were able to cope with high degrees of life change or low social support in ways that did not compromise the learning of their children. Low education mothers seemed to have less ability to do so.

The authors concluded that screening children without assessment of family and environmental variables is not effective. Any child assessment should include assessment of the family's ability to provide adequate support and "cognitive nourishment" to the child. This assessment should include the HOME, the social support available to the parents, the quality of the marital relationship, and the degree of stress experienced by the family and their resources for dealing with this stress. Perinatal assessment, assessment of the child's environment and the family ecology at 12 or 24 months would appear to yield the most useful information.

Many other studies have found that the children at the greatest risk are those that are both biologically and environmentally at risk. These children are doubly disadvantaged and represent the group with whom we should be the most concerned. (Cohen, 1983; Bennett, 1984) Coll (1985) found that teen pregnancy and obstetrical risk factors may have an additive adverse effect on newborn behavior. Those infants with higher fetal risk, shorter gestational age and younger mothers had lower scores on scales which measure their ability to regulate their state. A recent survey by the National Project 0-3 revealed that children with environmental risk are the least likely to be identified through state tracking systems or other identification systems even if they have double vulnerability with established or biological risk conditions.

The effect of environmental factors seems to be less detectable in the early years of life but becomes more apparent in the preschool and school age years. It appears that environmental factors are more important to the development of functions that mature later, especially language. (Siegel, 1985)

Development and Learning

Developmental delays have been explained by a variety of models and theories. The intrauterine period and the first two to three years of life are the most important for brain development. It is during this time that the infant is most vulnerable to physical and emotional trauma. The cumulative effect of clusters of prenatal, neonatal and environmental factors can, therefore, be viewed as moderately predictive of later developmental disability. Variability of individual development within high risk groups has been explained by a transactional process model. This model states that a child's biological characteristics are not fully expressed at the time of conception. Over time, these biological characteristics become more manifest, but are significantly influenced by the child's experiences within the environment. Thus, infants with similar biological risk factors may have different developmental outcomes, depending on the environment to which they were exposed. (Ramey, et al, 1982)

The theoretical concept of the mediated learning experience (MLE) describes two ways in which an individual is modified by interaction with the environment. The first way is through direct contact or exposure to stimuli. This stimulus-response kind of learning is the most basic. An example of this is learning not to touch a hot stove. The second way is through a human mediator who goes between the organism and the environment and mediates the experience to the organism. This represents a stimulus--organism-response sequence of learning. The public school system is an example of this kind of learning. This theory postulates that some kinds of learning require a human mediator. Cultural deprivation then is seen as a lack of opportunity for individuals to learn through the assistance of a human mediator (teacher). It may also explain why so many adults have not reached the formal operations level of cognitive development described by Piaget. Studies have shown a correlation between MLE ratings for children and later cognitive performance. (Klien and Feurstein, 1985).

Ramey, et al. (1982), describes the bidirectional influence of mother-infant interaction. This model explains the significant influence the infant can have on his own environment. An example of this is the premature infant who is less responsive to the mother, eventually "teaching" the mother to be less responsive in return. This results in less mother-infant interaction and a poorer environment for development of the infant. Mother-infant interaction has been studied in depth and been shown in numerous studies to have great measurable effect on the infant's cognitive, social, and affective development. Research continues into the specific dimensions of this interaction and which effects persist and how they are modified by subsequent experiences. (Tjossem, 1976, Eyres, et al., 1979, Hammond, et al., 1983)

Since each individual is different genetically as well as environmentally, wide diversity of behavioral outcome is found after similar damage. It is impossible to predict a behavioral outcome for any given child from a description of the biological insult. (Tjossem, 1976) There is a difference, however, between predicting a specific outcome for an individual child and predicting the level of risk for a group of children with similar

histories of biological and environmental insult. Research is demonstrating that such predictions can be made. (Bennett, 1984; Blackman, 1984; Dunn, 1980; Nichel, et al, 1982; Siegel, 1985)

Identification

The problem of identifying children in need of special services has been approached in a variety of ways. Risk registries, tracking programs, screening, and case finding and referral are the major ways of identifying children with health or developmental problems.

A risk registry is an example of primary prevention. It involves placing information about individuals with defined conditions or illnesses in a central file. Epidemiological investigation can then be done to pinpoint environmental contaminants or other causes for birth defects. Genetic counseling can be offered to persons on the registry who carry genetic predisposition for inherited disease. This could result in a lower rate of births of infants with genetically-based disability. Risk registries can also be used as a basis for tracking and in planning for health and education resources for the population. Washington State is implementing the Birth Defects Monitoring program which registers children up to age 14 with newly diagnosed handicapping conditions.

Screening involves both secondary and primary prevention. Its goal is early detection and treatment of health or developmental problems and the method involves a periodic assessment for health and developmental problems of large groups of children, ideally the entire pediatric population. Cost effectiveness is a concern since large numbers are screened. EPSDT is an example of a federal program aimed at general health and developmental screening of large groups of children. Recently, in combination with a case management system to improve administrative efficiency, EPSDT was able to show cost savings by reducing the need for episodic and acute care in eligible children. (EPSDT Program Report, FY 1984)

Tracking seeks to channel resources towards children with higher known risk of health or developmental disability. It is also an example of secondary

prevention since the aim is early diagnosis and treatment of handicapping conditions. The children are identified (usually at birth) by defined risk factors, tracked (usually through at least the first three years of life) and encouraged to have periodic evaluation to detect disability. Sixteen states have or are developing tracking systems.

Case finding and referral is the traditional method of identifying children with disability. Individual referrals are made to evaluation centers or specialists from primary health care providers, community service programs, or parents themselves. This is an example of tertiary prevention in that the illness or disability is already manifest and efforts are directed at limiting the degree of disability. It produces the poorest results in terms of minimizing handicap with children because care may not be initiated until complications have developed and valuable time has been lost.

Early Intervention

Early intervention is aimed at providing a service to the high risk or established risk child and his family which will promote the optimal functioning of the child and family. Evaluation of such efforts has been confounded by outcome measures which may not measure optimal functioning. Early evaluation of programs conducted during the 1960's and 1970's looked mostly at IQ scores as outcome measures. Many of these programs did not show positive IQ outcomes. Some of the programs did result in positive intellectual effects for children at ages two, five and ten and positive effects on the mother in relation to frequency of returning to work or school. Many studies showed positive long-term effects on the Home Observation for Measurement of the Environment Scale (HOME). (Ramey, et al, 1982)

The most effective programs were those that sought to strengthen the family involvement in the development of the disadvantaged child, specifically the mother-child interaction system. (Tjossem, 1976) Those programs which did not involve the parent (preschool-based or direct intervention with the child) showed little effect. (Tjossem, 1976)

When evaluating the effectiveness of early intervention, IQ scores should not be used exclusively. Improvement in functional, adapative behavior (social and self-help skills), enhanced daily care (feeding, positioning, interacting) and better family functioning are all appropriate outcome measures for early intervention programs and are directly related to the goals of such programs. (Bennett, 1985)

Head Start is an example of an early intervention program for children at risk for developmental delay due to environmental factors. Early evaluation showed that IQ gains were lost by early elementary school. Recently, long-term studies have shown some persistent late effects such as improved school functioning, less need for special education, less grade retention, and less school dropout for program children. Programs beginning before three and involving the parents seemed to be the most effective. (Bennett, 1985) Ramey, et al, 1985, conclude that the most intensive programs in terms of hours and years of contact with families and many hours of direct contact with children are the most likely to have a positive effect on the children's intellectual outcome.

Nursing Care

Nursing has long been involved in providing a range of services to high risk infants and families. Often these services are provided in the home. Infants who are less responsive, or whose response cause them to be categorized as "difficult," whose sleep and wake cycles are disorganized, who present with handicapping conditions which require large amounts of family time, financial and emotional resources, and who may be born into families already stressed by their socioeconomic situation are at high risk not only for developmental delay and poor school functioning, but family disorganization (divorce, neglect or abuse). Research has shown that NICU nurses' clinical assessment and prediction of parent-child relationships in the hospital is significantly correlated with HOME scores at nine months corrected age. (Allen, et al, 1982) Ways to intervene with families who

demonstrate these high risk behaviors are being investigated. Kathryn Barnard, R.N., Ph.D., Professor of Nursing, at the University of Washington School of Nursing is now testing a set of nursing protocols to assist nurses in providing high quality nursing care to families of premature infants.

Local public health nursing departments provide home visits to infants and families which include a range of services. These services include assessment of the infant and family, parent-infant interaction, teaching of child care and development, specific interventions to be used with the infant, and reinforcement of positive interactions. Referral to other private health care providers and community services is also provided. Coordination of care is an essential role of the public health nurse in ensuring that each child receives individualized care for his/her specific needs.

In Ontario, Canada, Clemmens (1982) found that a family-oriented follow-up program, which included the perinatal period through five years of age with integration into the school system, was a very effective means of providing care to high risk infants and their families. Risk criteria were premature infants under 1000 grams birth weight or less than 1500 grams birth weight with other complications, small for gestational age infants, infants with congenital defects, birth trauma, anoxia, complications for the mother in the perinatal period, and infants where there was an indication of deprivation or failure to thrive.

Home visits were made by the public health nurse with ongoing programming as needed. These home visits included physical exams and assessments, specialized nursing care as required, postpartum care of the mother, administration of several developmental and cognitive functioning tests for infants, infant stimulation, case conferences with other providers as needed, provision of liaison with other services, encouragement of continued parent involvement, parent education classes, and health education and counseling to the family.

The acceptance by the parents was excellent, and working relationships with other health professionals have been enhanced by the development of the high risk infant follow-up team approach within the public health department. They receive regular referrals from pediatricians, neonatologists, and family physicians in the area.

Federal and State Programs

Major federal programs have been developed to address the above issues. Early Periodic Screening, Diagnosis and Treatment (EPSDT) provides screening for Medicaid eligible persons from birth to 21 years of age. The Education of the Handicapped Act of 1975 (Public Law 94-142) was designed to ensure that all handicapped children receive appropriate education and services designed to meet their needs.

Child Find is each state's methodology to identify children with disabilities at early ages (three to five years) and enroll them in school programs. The state of Washington began enrolling children in need of services in school programs at age three in the fall of 1985. In addition, Head Start programs are providing early education opportunities for disadvantaged children and families.

Each state also has individual programs designed to meet some of these needs. Unfortunately, coordination and cooperation between health, education, and social services was not a part of the early planning for these diverse programs. Lack of coordination continues to be a barrier to a comprehensive plan to meet the needs of at-risk and handicapped infants and children. Project 0-6 is developing a statewide plan to address this issue.

ANALYSIS OF STATE TRACKING SYSTEMS

Seventeen states are currently involved in developing or implementing tracking programs: Delaware, Iowa, Nebraska, New York, North Carolina, Utah, Tennessee, Maryland, Maine, New Jersey, Ohio, Washington, Kansas, Wyoming, Hawaii, Texas and Pennsylvania. Some of these programs have developed independently, many have benefitted from the experience of other states and have built informal networks to exchange information. The National Center for Clinical Infant Programs (NCCIP) has been the main vehicle for formal meetings, information exchange and policy planning related to the development of comprehensive service systems for disabled and at risk children. It was funded in 1983 by the Federal Division of Maternal and Child Health. The State Technical Assistance Resource Team (START) at Chapel Hill, North Carolina, has done facilitation of information exchange between states interested in early childhood special education. In August 1985, they published the State Resource Exchange Directory which lists state by state information on resources, materials and skills, as well as information on resource needs. The Washington State High Priority Infant Tracking project has provided information, materials and/or consultation to Alaska, the Kennedy Institute in Maryland, North Carolina, New Jersey, Pennsylvania, Kentucky and Indiana.

Tracking systems operate differently from state to state. The main goal of all of them is to prevent vulnerable children from being lost to follow-up by the health care system and promote early identification of children in need of special services. Most programs are operated by the health care system, although some early childhood educators are becoming interested in the benefits education could reap from tracking systems. Most of the infants enrolled in tracking systems are identified in the hospital.

Tracking is generally accomplished by the local health departments - sometimes through continuing contact with the primary care provider as is done in Washington, and some through public health nurses or pediatric nurse practitioners making regular contacts with the family for screening and referral. Some tracking programs use standardized screening tools such

as the Denver Development Screening Test, Denver Prescreening Developmental Questionnaire, Brazelton Neonatal Behavioral Scale, or the Bailey Infant Assessment. The Washington State Program currently does not ask for information on what screening tool is used by the primary care provider in assessing a child. Some programs serve as an interagency coordinating system and have begun to develop centralized computer registry systems which are needed to optimize efficiency and utilization. Washington's program has not yet developed this function.

The enrollment criteria vary from state to state and the numbers of infants currently served varies as well. As of June 1985, New York had 2,600 children enrolled with 600-700 new children identified per month. They expect to be tracking 38,000 children by 1989. Some states require parental consent before enrollment. Other states do not, sometimes because of enabling legislation. (For example, because of enabling legislation, the Washington State Birth Defects Monitoring Program does not need parental consent for children to be entered into their registry.) Most programs are funded by block grant or state monies.

The National Center for Clinical Infant Programs' Project 0-3 sponsored meetings during the summer of 1984 for participating states interested in developing comprehensive service systems for disabled and at-risk children. The states participating included Maine, New Jersey, Maryland, North Carolina, Ohio, Iowa, Texas, Utah, Washington, and Hawaii. The meetings addressed the following issues:

1. Legislative mandates for serving disabled and at risk children from birth to three--advantages, barriers, pitfalls, and alternatives. ("There Ought to Be a Law")

2. Systems for identifying and tracking high risk (high priority) infants. ("Keeping Track: Tracking Systems for High Risk Infants and Young Children")

3. Outcomes evaluation. ("Program Evaluation: Issues, Strategies and Models)

The outcome of the first meeting recommended that some form of well-articulated public policy statement should be made on a statewide basis. This could take the form of mandatory legislation, phase-in legislation, nonmandatory legislation, executive orders, or regulations. Such a public policy statement ensures fairness and access to high quality services, makes wise use of limited resources and provides for program continuity. Washington currently mandates in the 1985-86 school year that preschool services will be available for children ages three and up. In addition, birth defects legislation requires physicians to report any cases of children with a variety of handicapping conditions.

The second meeting, which discussed tracking systems, included the following criteria for an effective tracking system:

1. Begin prenatally.

2. Focus on parent and family strengths and needs, as well as the target child.

3. Ensure smooth transition for child and family between services designed for a particular stage of development and between agencies.

There is no concensus on the best predictors of difficulty in development. Criteria vary from state to state, but low birthweight, hospitalization in a neonatal intensive care unit, or birth to an adolescent mother are frequently used indicators. It is not yet known the degree to which using broader or narrower definitions of a given criterion will sharpen the focus on the target group without leaving out many who should be included. North Carolina has recently lowered the criteria for low birthweight from 2500 to 2000 grams and North Carolina and Washington have both lowered the criteria for maternal age to 14 and 15 years, respectively. Systems which include both parental risk factors, including psychosocial concerns identified at the time of childbirth, and infant criteria may be the most predictive of future developmental problems. However, few states consider environmental/social risk factors in the tracking system. Washington State does include parenting and other environmental risk factors.

In relation to deleting a child from a tracking system, the NCCIP participants felt that dropping any high risk child already in a tracking system seemed unwise due to the fact that we know very little about the etiology and onset of developmental problems. In Iowa, it was found that approximately 20 percent of the biologically at risk infants born in a given year required special educational and therapeutic services in the early years of life. Of the remaining 80 percent, one-fourth manifest emerging learning difficulties warranting special assistance at school entry. There is a great need for better screening instruments and techniques which have better predictive value.

Issues of confidentiality are raised when any tracking system is considered. Utah addresses the confidentiality issue by taking the position that its tracking system is the guardian, not the owner of information with responsibility for making sure that information is used for the child's benefit. Parents are often more willing to give data to a local health department than a state agency . Tracking system information to be used for needs assessment and planning can come from aggregated data with the names omitted. Even if services are not available to the children identified in the tracking program, the identification of needs can stimulate the development of appropriate programs.

The role of the parents in the tracking system should be to see themselves as owners of information about their child with the right to obtain all information entered into and generated by any data collection system and with the authority to release data to themselves for review or to specific agencies which might be serving their child. In Utah, the parents would agree to participate in a Central Registry as they requested services. It was recognized that for some parents it may not be appropriate or possible for them to undertake responsibility for advocacy, but that the tracking system might nevertheless serve a useful function by advising parents of advocacy opportunities and teaching them advocacy skills.

The NCCIP participants agreed that health providing agencies should have primary responsibility for a tracking system. In Utah, a newborn questionnaire which includes a set of questions on the birth certificate, is hoped

to be able to identify 70 percent of those who will later be identified as handicapped in the school system. If the tracking system plans to address parent psychosocial and emotional status, involvement of the state mental health agency will be needed. Administrative tools such as inter-agency agreements, memoranda of understanding, and common computer registry forms would contribute to the success of a tracking program.

It was felt that it might be desirable to use a non-state agency, such as a university, Developmental Disabilities Council, or consumer group, to operate a follow-up system. Such an organization might simply function as manager of a tracking system and, more importantly, as an advocate for the child and the family. Washington State currently contracts with the University of Washington Child Development and Mental Retardation Center (CDMRC) for project coordination and data analysis.

In Texas, the Project 0-3 Committee explored ways to link data bases and the advantages of having a centralized tracking system. They felt that the following four reasons for a tracking system work to the advantage of the population at large and of all agencies.

1. To verify services provided and to provide epidemiological data for the population.

2. To provide data for the justification of new funds.

3. To provide data for effective planning for the special education needs of children.

4. To provide the population from which to draw representative research to answer questions on cost effectiveness and educational effectiveness. ("Keeping Track," page 9)

Funding will determine in the following four ways the basic goals, structure, longevity, and services offered by the tracking system:

1. The system's entry criteria. The less money available, the more limited the system's criteria will have to be.

2. The system's capacity for outreach activity.

3. The quality and the quantity of the program staff.

4. The longevity of the tracking system.

Without reasonable long-term assurance of funding, tracking systems are unlikely to be able to meet either the data collection or service goals for which they were designed.

In summary, the NCCIP group felt that some type of tracking system provides a major means of helping children reach their full potential and ultimately prevent disability as well as providing a data collection system about vulnerable children and their families.

WASHINGTON STATE

HIGH PRIORITY INFANT TRACKING PROJECT

Beginning in October 1982, the state Maternal and Child Health Services, in coordination with the University of Washington, implemented the High Priority Infant Tracking Project (HPIT) as a pilot project in Whatcom County, Washington. To further evaluate the effectiveness of this tracking system, Thurston County was added to the pilot project as a matched county in May 1984. The primary objectives of this project are as follows:

1. To help parents keep their child under the care of a primary physician.

2. To promote early identification of infants requiring further evaluation or services.

3. To assist in planning for the health and educational needs of the children of Washington State.

This program identifies high priority infants according to "high priority" indicators listed on the "Identification Form" (see Appendix A). This form includes such indicators as low birth weight and other physical conditions which put the infa at risk, as well as significant environmental, social, or parenting risks. After the "Identification Form" is completed, consent is obtained from parents and the infant's primary care provider. A copy of the form is sent to the public health department, and enrollment into the tracking system is initiated. A "Tracking Form" (Appendix B) is sent to the infant's primary care provider at 3 months, 6 months, 12 months, 18 months, 24 months, and 36 months. Questions regarding the infant's health and developmental status, use of community services, and whether or not the infant is still receiving ongoing health care are asked on the tracking form. If the health care provider indicates the infant is not receiving care, the public health nurse attempts to locate the family and connect them back into the health care system.

The HPIT program has now completed both a pre-pilot study and the first three years of the pilot study. The data is derived from findings on 638 infants identified from six hospitals, two public health departments and private health care providers caring for infants residing in Thurston and Whatcom counties.

Public health departments in both counties have successfully documented that greater than 85 percent of the high priority infants have been maintained in the health care system once enrolled into the tracking system. In contrast, a pre-pilot study in Thurston County which examined continuity of care for high risk infants born before the tracking program was initiated, showed that only 15 out of 22 infants (68%) actually received care from the physician listed on hospital records as the primary physician. Thirteen out of 22 infants (59%) remained in care during the first year of life, and by the second year only 7 out of 22 (32%) of the high risk children remained with the same primary care physician. The average age at which infants dropped out of care was 8 months. McLaughlin, et al., has also shown that high risk infants can be very difficult to trace retrospectively without any tracking system in place. Over 50 percent of the infants in his study could not be located at the time of the study for follow-up information. This tracking system has thus far changed this percentage to less than 15 percent of high priority infants presently being lost to follow-up once enrolled into the tracking system. This indicates the first objective, to help parents help keep their child under the care of a primary physician, has been met.

The second objective of promoting early identification of infants requiring further evaluation or services has also been addressed. The data analysis indicates infants can be correctly identified as having a health concern at three months, and having a developmental concern at six months. Identifying these infants at these young ages can assist in assuring prompt follow-up and referral for needed services. Approximately 40 percent of all infants tracked later develop health concerns. Approximately 20 percent of all infants tracked experience developmental problems.

The third objective of planning for the health and educational needs of the children of Washington State has also been considered. In Thurston County about 40 percent of the children tracked are using other community services, primarily health department services. Aggregate information about children with disabilities identified through the tracking program can be shared with school districts in each county. This will help them to prepare to meet the needs of these children. More work needs to be directed at the process by which this will occur.

A cost analysis has been conducted for the time period July 1, 1984 through June 30, 1985. This analysis showed that the total cost of enrolling and tracking a child on HPIT for one year averaged about $122 per child. It costs the hospital about $11 to identify and enroll an infant, and it costs the primary care provider $4 to participate in the tracking program per high risk child followed. The bulk of the expense with HPIT resides with the coordination, evaluation, and research components of the program which are crucial to establish whether the program is effective and efficient. This information feeds into state planning regarding the best methods of preventing, identifying, and intervening with disabled children. Much of this cost will be reduced as more counties utilize the tracking process. These costs will be spread over more children and the project's cost effectiveness will be increased.

Besides evaluation of the program itself, the effects on the health care system need to be documented. Many of these effects are benefits of this program which were not foreseen when originally planned. Conversations with local health personnel involved with this project reveal the following unplanned benefits:

1. Public health nurse referrals in both counties have increased dramatically since this project was initiated. One year after implementation of HPIT, MCH referrals in Thurston County rose 27 percent over the previous two years. Two years after implementation, MCH referrals from St. Joseph's Hospital to Whatcom County Health Department rose 52 percent. Other factors could account for some of the increase, but the PHNs in the counties felt HPIT was largely responsible.

2. The liaison between community physicians, hospital personnel, and the public health departments has improved since this project was started. In both counties, community health nurse and hospital nursery nurses have improved communication and cooperation. In Whatcom County, public health and hospital nurses cooperate in teaching mother and infant classes on the postpartum unit. Thurston County PHNs meet hospital staff for lunch to provide needed feedback on public health referrals.

3. Returning high priority infants to the health care system improves the practice of community physicians by keeping high risk children in their care. By seeing children with complex health or developmental problems, physicians remain familiar with how to recognize, treat, and refer children with these problems. Higher quality care is delivered when continuity with the primary provider is encouraged.

4. The liaison between the state Parent and Child Health Services, the University of Washington, the public health departments and the participating hospitals has improved. Two state advisory committee meetings and two local advisory committee meetings in each county are held each year. All interested and involved parties can problem-solve and share ideas and concerns at these times. This face-to-face contact makes subsequent mutual effort easier and more likely to occur.

5. Hospital nursing staff feel more comfortable identifying high priority infants than before the project was started. The clarity of the high risk criteria encourages direct PHN referrals for these children as well as enrollment in the tracking project. Thus, better referrals for PHN services are made by the hospital nurses.

6. The hospitals have utilized data generated from the project to assess their neonatal population. One hospital used its rate of high priority infants to evaluate referral patterns and plan to meet the needs of those infants.

All of these factors work together to strengthen the interagency and inter-provider linkages so that the health care system works more effectively to meet the needs of the individual child. The communication flow is enhanced. Problems with children who "fall through the cracks" or whose needs are incompletely met are brought to light and solutions are sought. One child was referred by his primary physician for a neurodevelopmental evaluation and then was referred to another tertiary care center for treatment. CCS was involved in paying for the evaluation. The child was also receiving services from WIC. The PHN visiting the family assessed that the parents were receiving conflicting information and instructions from the various providers and they were extremely confused and frustrated in their attempts to help their child. After a conference between the primary physician and the PHN, a case conference which included both referral physicians who had seen the child was arranged so that the child's needs were assessed and intervention planned from a wholistic perspective. Continued follow-up by both the primary physician and PHN will ensure that this child continues to receive comprehensive care to cope with his disability in an optimum fashion.

The role of the PHN in supporting the parents of high risk infants is important. Some parents do not understand the importance of returning their infant to the primary care provider for periodic care, some have difficulties dealing with the stress of having a premature or irritable infant. Often these high risk infants have a guarded prognosis if they experienced difficulties in the NICU from birth events or infection. Parents play a waiting game to see if their child turns out "normal." The child may experience some neurodevelopmental abnormalities or delays. This creates much stress and anxiety for the family. They need someone to verbalize these fears to who can help them cope while at the same time teaching them to interact positively with their child.

For the upper income parents, the PHN serves as a resource for what is available in the community to meet the special needs of their child. It is the PHN's task to remain informed on the whole range of community health resources available in the community and in the state. Such information

may be difficult and time consuming to obtain for someone unfamiliar with the health care system. For the poor or uninsured family who finds it difficult to find and pay for expensive health care services, the PHN uses her knowledge of sources of financial assistance and low cost health care resources in the community. Often these families also need support and intervention for the multiple factors of poverty, lack of job skills, lack of understanding about basic health practices and nutrition, and, sadly, family disruption due to adolescent parenting, alcohol, drug abuse, or child abuse.

While there is a broad range of community services available in most counties in Washington State, resources for low income families are very limited. PNHs provide a valuable service in assisting clients to utilize the services that are available, and in identifying gaps where they exist. The High Priority Infant Tracking Project has stimulated the unanticipated outcome of encouraging coordination of the health care systems in the counties where it is operating. Currently a task force from the project is looking at ways the health care system can interface with the educational system to help meet the needs of the child who seeks services from both the school district and the health care community. This is also one of the goals Project O-6 is involved with in this state.

RECOMMENDATIONS FOR PROGRAM IMPROVEMENT

The present High Priority Infant Tracking (HPIT) program has several areas where improvements are under consideration.

1. An organized system for providing feedback to the nurses and physicians involved with the program needs to be instituted. The program has a well developed evaluation component which includes extensive data analysis by the University of Washington. At present, no regular, periodic and concise feedback on these outcomes are provided to the professionals involved, especially the hospital staff whose support for the program is crucial to its success. Without this feedback, interest in the program will wane, less children will be identified and the program's effectiveness will rapidly decline.

2. The Birth Defects Monitoring Program (BDMP) has been implemented in Washington State and ways to integrate these programs need to be explored.

3. The identifying criteria need to be revised to reflect the latest information on important risk factors (prenatal, biologic and environmental) to improve efficiency in data collection. The tracking forms need to be revised to clarify what community services the child is utilizing, the date when the child was last seen and how developmental evaluation was arrived at (parent report, standardized tool, observation).

4. A central registry system needs to be planned which could be used for the implementation of HPIT and BDMP as well as provide a central information and tracking center for high risk and handicapped children statewide. Ideally, such a system should be accessible to the health, education, and social services systems. Parental consent would be obtained for entry of data into the computer with a thorough explanation of the possible uses of such data. Such a system could be used for retrospective epidemiological investigation, tracking, data analysis of the incidence and prevalence of handicapping conditions and

demographic distribution and patterns of care. The establishment of such a central system would eliminate the need to develop a new data base each time one of the above service systems began a new program. It would also greatly reduce the paperwork load in the present system.

5. A stable funding source needs to be identified. The tracking system developed by HPIT is best conducted on a statewide basis to provide equitable distribution of services across the state, provide tracking for those children who move to another county, and to reap the most benefit from the analysis of the service delivery system.

6. The current system of tracking children through the primary care providers should be evaluated to see if another system might be more efficient and create less paperwork for the physicians. If the public health department conducted a developmental evaluation using a standardized tool on all identified children at periodic intervals and at that time assessed whether they were in the care of a primary provider, it would eliminate a considerable amount of paperwork for these providers. It would also provide consistent information on developmental status, maintain a current address for all identified children at the health department and facilitate direct referral to the school district for those children in need of special school services. It would increase the public health department's direct involvement with identified children and thereby increase those costs. A related issue that needs to be assessed is whether the current system is effective in providing prompt referral to early intervention services for those children who need it.

7. Consideration should be given to what benefits might result from enabling legislation which would facilitate identification of infants from birth certificate information, Birth Defects Monitoring registry, and other sources which at present are not accessible to HPIT. Such legislation could also mandate sharing information between agencies. New York presently utilizes such a system and takes the position that it is a state responsibility to provide comprehensive services to at risk or disabled children and that confidentiality should not be a

barrier to providing this service. Utah also takes the position that a greater disservice is done to the public and individuals by allowing confidentiality to stand in the way of developing comprehensive, efficient systems to serve needy persons. They assert that more lawsuits are generated by persons charging that professionals have failed to share critical information whereby harm has resulted rather than the reverse.

8. Every effort needs to be made to include all agencies and organizations involved with at risk and handicapped children in planning for the future of HPIT. A tracking system merely makes it possible for the health, education and social services systems (both public and private) to operate effectively and at the earliest possible time to ameliorate the effects of potentially handicapping conditions on children's futures. Because of this role, HPIT could have broad implications for improving the outcomes of these children, but it also must have the support of these various groups in order to be effective and fiscally supported. Tracking systems are thwarted by fiscal insecurity because they require sustained effort over many years in order to reap maximum benefits. Working together, such a program can be implemented effectively, and in the end will save each of these service delivery systems the resource drain of developing outreach and child find efforts independently.

SUMMARY

It is clear that high risk infants with a variety of risk criteria including biological and environmental insults end up with physical, learning, psychological, and psychosocial problems. Those infants with the lowest birthweight (under 1000 grams), infants of lower socioeconomic status, and those with biological and neurological handicapping conditions and those children whose family environment does not meet their needs are at the greatest risk.

A tracking system provides a means of encouraging these infants to have continuing follow-up with the health care and social service systems. Without such a tracking program, approximately 50 percent of these children will be lost to care until school age. As advances in neonatal intensive care improve, lower and lower birthweight infants are surviving and ultimately become part of the school population. As the stresses on the family increase, there is more family isolation and the rate of single parent families increases. More children will be raised in these compromised environments.

1. In the state of Washington, the High Priority Infant Tracking program is showing itself to be productive and viable (it is possible to track and ensure follow-up care for over 85% of children) and these children do appear to have a higher percentage of health and developmental problems than the average population.

2. Washington State has been a pioneer in the development of a tracking system, building on the work of Iowa and North Carolina. Washington State's tracking program, by including environmental as well as biological risk factors, is one of few tracking programs in the country looking at these dual issues. The incorporation of a strong program evaluation component is beginning to demonstrate solid statistical evidence of the program's effectiveness. Continuation of the tracking program could result in expanding our knowledge of outcomes of high risk infants.

3. The tracking system has provided a structure for the development of community networks, described by the public health-nurses conducting the program in both Whatcom and Thurston Counties as extremely beneficial to the clients.

4. An effective, efficient tracking system will provide increased access to care for infants, and a solid basis for many well-child and handicapped children programs, as well as data for epidemiological studies.

5. The school system requires information regarding the number of high risk infants in the community and their level of disability. The tracking system could meet this need if appropriate coordination with the education system is established and confidentiality issues are resolved.

6. The problem of child abuse is rising in the state of Washington. High Priority Infant Tracking may provide an early means of identifying families that are dysfunctional and, therefore, prone to the problem of child abuse and neglect. It could provide a means of initiating primary prevention for these problems.

7. The problems that these children experience will not disappear. Some means of identifying and delivering care for these children needs to be provided. At the present time, tracking seems to be the best initial means of reaching these goals.

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Washington State

High Priority Infant Tracking Project

DATA ANALYSIS SUMMARY REPORT

(October, 1982 to March 1, 1986)

Patricia J. Biro, M.Ed. Coordinator
High Priority Infant Tracking Project
and
Michelle A. Bell, Ph.D.
Maternal-Child Health Services
School of Public Health and Community Medicine
University of Washington
Seattle, WA 98195

ACKNOWLEDGEMENTS

This project is supported by the State of Washington Maternal Child Health Services. The author wishes to thank the participating hospitals, local health department staff, and the participating staff at the University of Washington for their assistance in the preparation of this report.

The assistance and guidance of Mary Hammond, Ph.D., Evaluation Consultant, Deborah Padgett, RN, MN, and Melinda Knutson, RN, PNP, MPH was greatly appreciated. Additionally, thanks are extended to the parents and physicians whose participation has made this project possible.

ABSTRACT

WASHINGTON STATE HIGH PRIORITY INFANT TRACKING PROJECT

In 1982 the Washington State Maternal/Child Health Services Division in coordination with the University of Washington implemented a pilot study to determine the effectiveness of a tracking program to maintain high risk infants in continuing health care, determine health and developmental outcomes, and survey the use of community resources in this population.

Whatcom County has completed three years of pilot study. Thurston County was added in May 1984 and has completed twenty-one months of participation. 638 infants have been identified as "high priority" in six participating hospitals in two counties. Infants are identified with the first 30 days of life according to 17 criteria incorporating medical, social and environmental risk factors. The project has enrolled 78% of the eligible infants. Data is collected at pre-determined tracking points of 3, 6, 18, 24 and 36 months via postal questionnaire to the primary care provider. Community health nurses follow up on any infant who drops out of care during the tracking period, and reconnects the family with the health care system when possible. Both counties have maintained greater than 85% of the high priority infants identified and enrolled in ongoing healthcare and developmental surveillance.

The largest group of high priority infants had low birthweights 2500 grams (N=226). Other frequent indicators are respiratory problems (N=99) and birtn defects (N=103) infants were identified as doubly vulnerable by presenting both medical and environmental/social/parenting risk factors. The majority of infants were identified by presenting more than one eligible criteria (66%).

Medical problems identified at 3, and 6 months were predictive of later medical problems. (p .05). Developmental problems identified at six months were predicative of later developmental problems. A significant relationship (p .05) between early health problems and later developmental problems was identified. The six month tracking period proved to be the most predictive for later health and/or developmental outcomes. The overall incidence of health problems in the sample population was forty percent (40%). Developmental problems were noted in approximately twenty percent (20%).

The most frequently reported community resource used by high priority infants and their families was the local health department. Referral to other specialists/consultants were used by four percent of the cases. Most infants were monitored by a primary care provider in their local community.

Tentative conclusions based on three years of data collection indicate that an organized, systematic tracking program can keep high priority infants in ongoing primary health care and assure timely identification and referral for further evaluation of potential developmental problems.

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INTRODUCTION

In October, 1982 the Washington State Maternal and Child Health Services, in coordination with the University of Washington, implemented the High Priority Infant Tracking Project (HPIT) as a pilot project in Whatcom County, Washington. To evaluate the effectiveness of the tracking system, Thurston County, Washington was added to the pilot project as a matched county in May, 1984. The primary objectives of the project are as follows:

1. To help parents keep their child under the care of their primary physician.

2. To promote early identification of infants requiring further evaluation, or services.

3. To assist in planning for the health and educational needs of the children of Washington State.

Infants enter the HPIT project by first identifying high priority infants according to "high priority" indicators listed on the IDENTIFICATION FORM (see Appendix A). Infants may be identified using one or more of the seventeen criteria including medical, social, parenting, or environmental risk factors. The IDENTIFICATION FORM is then completed, noting the risk factors identified, and consent is obtained from the infant's parents and the primary health care provider. A copy of this form is then sent to the public health department, and enrollment into the tracking system is completed.

A TRACKING FORM (see Appendix B) is sent to the infant's primary care provider at three months, six months, twelve months, eighteen months, twenty-four months, and thirty-six months. This form requests information regarding the infant's health and developmental status, use of community services and the status of ongoing health care. If the health care provider indicates the infant is not receiving care, the community health nurse attempts to locate the family and reconnect them with the health care system. Follow-up activities by the community health nurse may include written communication with the family and the primary care provider, telephone calls and home visits.

The High Priority Infant Tracking Project has now completed a pre-pilot study and three full years of the pilot study. The following data is derived from the analysis of information obtained from six participating hospitals, two public health departments and private health care providers caring for infants residing in Whatcom and Thurston Counties.

During the time period from October 1, 1982 to March 1, 1986 389 infants from Whatcom County and 249 infants from Thurston County have been identified as "Hign Priority." This report provides a description of the data obtained from these 638 infants as well as tracking information for 497 infants who are participating in the tracking phase of the project.

WHATCOM COUNTY

Whatcom County has now completed three years, five months of the pilot phase of the High Priority Infant Tracking Project. During the period from October 1, 1982 to March 1, 1986 three hundred and eighty-nine (389) infants have been identified as "High Priority." Sixty-eight percent (68%) or 267 infants have been successfully enrolled into the project and are at different tracking stages. The remaining 122 infants were not enrolled into the project for the following reasons:

-	Missed:	2 infants	(2 percent)
-	Physician Refusal:	73 infants	(60 percent)
-	Parental Refusal:	11 infants	(9 percent)
-	Adopted:	8 infants	(7 percent)
-	No Parent Signature:	12 infants	(10 percent)
-	Moving:	6 infants	(5 percent)
-	Baby Expired	1 infants	(.5 percent)
-	Wrong County	3 infants	(2.5 percent)
-	No Reason/Blank	6 infants	(5 percent)
			100 percent

Identifying Hospitals

The infants included in the High Priority Infant Tracking Project were primarily identified at three hospitals known to care for infants from Whatcom County, Washington. These hospitals include Children's Orthopedic Hospital, Seattle, Washington; University Hospital - Seattle, Washington; and St. Joseph's Hospital, Bellingham, Washington. Additionally, infants missed as high priority during their hospitalization, or born outside of the hospital can be later identified either by the Public Health Department or the infant's private health care provider. Infants can be identified at any time during the first thirty days of life through physician's request, home visit by a community health nurse or well child visit. The number of infants identified by each individual source is as follows:

Children's Orthopedic Hospital	21 cases	(5 percent)
University Hospital:	11 cases	(3 percent)
St. Joseph's Hospital:	350 cases	(90 percent)
Public Health Nurse/ Physician	7 cases	(2 percent)
Total	389 cases	

WHATCOM COUNTY

Number of Infants Identified Per Pilot Project Year:

The pilot project for Whatcom County began in October, 1982. As can be seen below, the numbers of infants as 'High Priority' and have 'Identification Forms' completed has increased with each project year:

-	October 1, 1982 to December 31, 1982	11 infants (3.6 per month)
-	January 1, 1983 to December 31, 1983	59 infants (4.9 per month)
-	January 1, 1984 to December 31, 1984	152 infants (12.6 per month)
-	January 1, 1985 to December 31, 1985	156 infants (13.0 per month)

Whatcom County births at St. Joseph's Hospital during the pilot project years have averaged approximately 1200 births per year. Approximately 10 to 12 percent of these infants are estimated to be "high priority." This indicates approximately ten to twelve infants per month should be identified as high priority at St. Joseph Hospital. The 1984 and 1985 pilot years appear to meet this estimate, based on the assumption that ninety percent (90%) of the eligible infants in Whatcom County are identified at St. Joseph Hospital.

Tracking Process

Once an infant is identified as high priority, and both physician and parental agreement to enroll the infant into the tracking program is obtained. The infant then is placed on the tracking schedule of 3 months, 6 months, 12 months, 18 months, and 36 months. All 267 infants with completed 'Identification Forms' and appropriate consents obtained have been placed on this schedule by the Whatcom County Public Health Department, and are presently at different stages of the tracking program.

The numbers of completed forms for each tracking period is depicted in TABLE 1.

TABLE 1
HPIT Project: Whatcom County
Completed Tracking Forms

Tracking Period	Number of Forms Completed
3 months	209
6 months	189
12 months	114
18 months	70
24 months	39
36 months	7

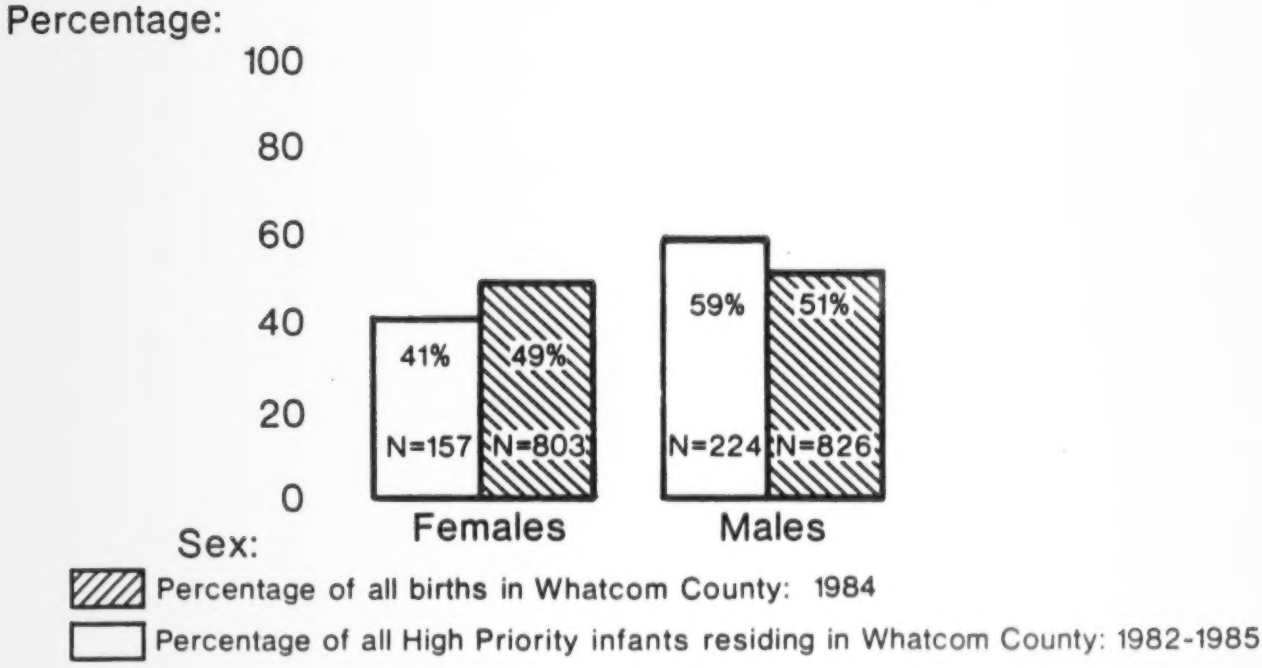
Characteristics of Whatcom County High Priority Infants

Sex:

Fifty-nine percent (224) of the high priority infants were male, 41% (157 infants) were female. The sex of the infant was not reported in eight cases. This preponderance of males to females compared with the reported county distribution is shown in Figure 1.

Figure 1:

Sex of High Priority Infants Compared
With Whatcom County Births in 1984

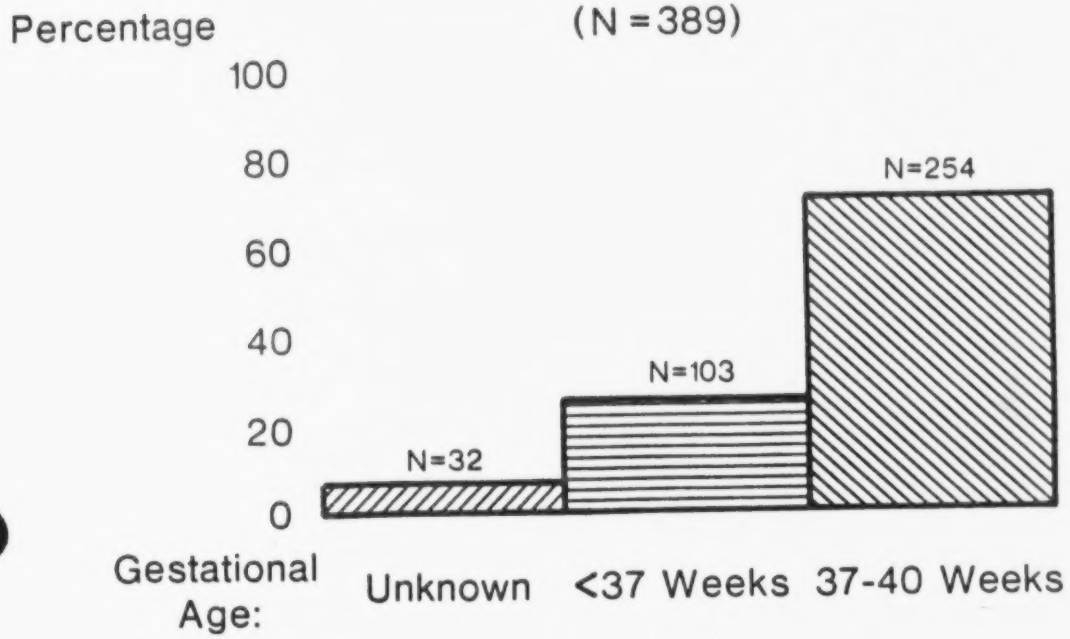


Gestational Age:

Twenty-six percent (103 infants) of the high priority infants identified in Whatcom County were born before 37 weeks gestational age. Seventy-one percent (254 infants) were born between 37 and 43 (full term) weeks. Eight percent (32 infants) of the cases did not report the gestational age. See Figure 2.

Figure 2:

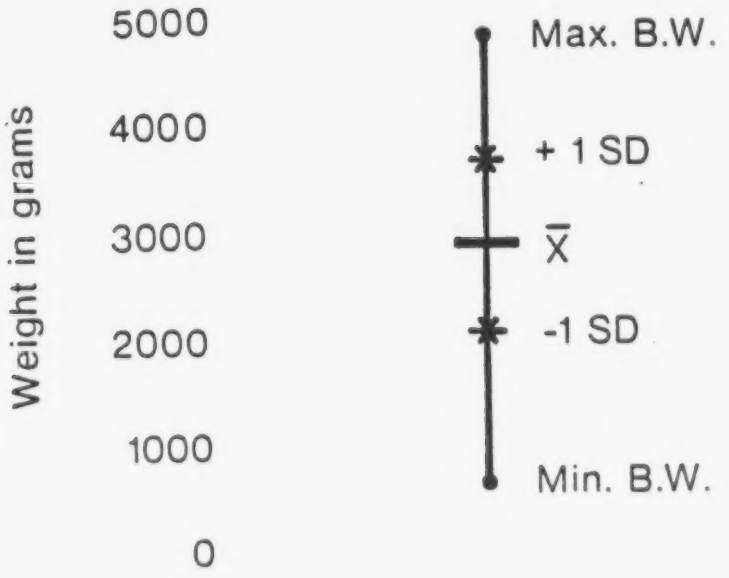
Gestational Age of High Priority Infants
Residing in Whatcom County
(N = 389)



Birthweight:

The mean, or average birthweight for these infants was 2895 grams (S.D.=806 grams), with a range of 660 grams to 4848 grams. An illustration of the average birthweight for Whatcom County High Priority Infants is found in Figure 3.

Figure 3:
Average Weight of Whatcom County
High Priority Infants



(Average weight = 2895 grams; SD = 806 grams)
(Minimum weight = 660 grams; Maximum weight = 4848 grams)

Identicators of High Priority:

Each infant identified as "high priority" in Whatcom County had up to five different criteria checked on the 'Identification Form.' Table 2 indicates the number of times an indicator was checked for the 389 identified high priority infants up to March 1, 1986. FIGURE 4 further illustrates the distribution of high priority indicators.

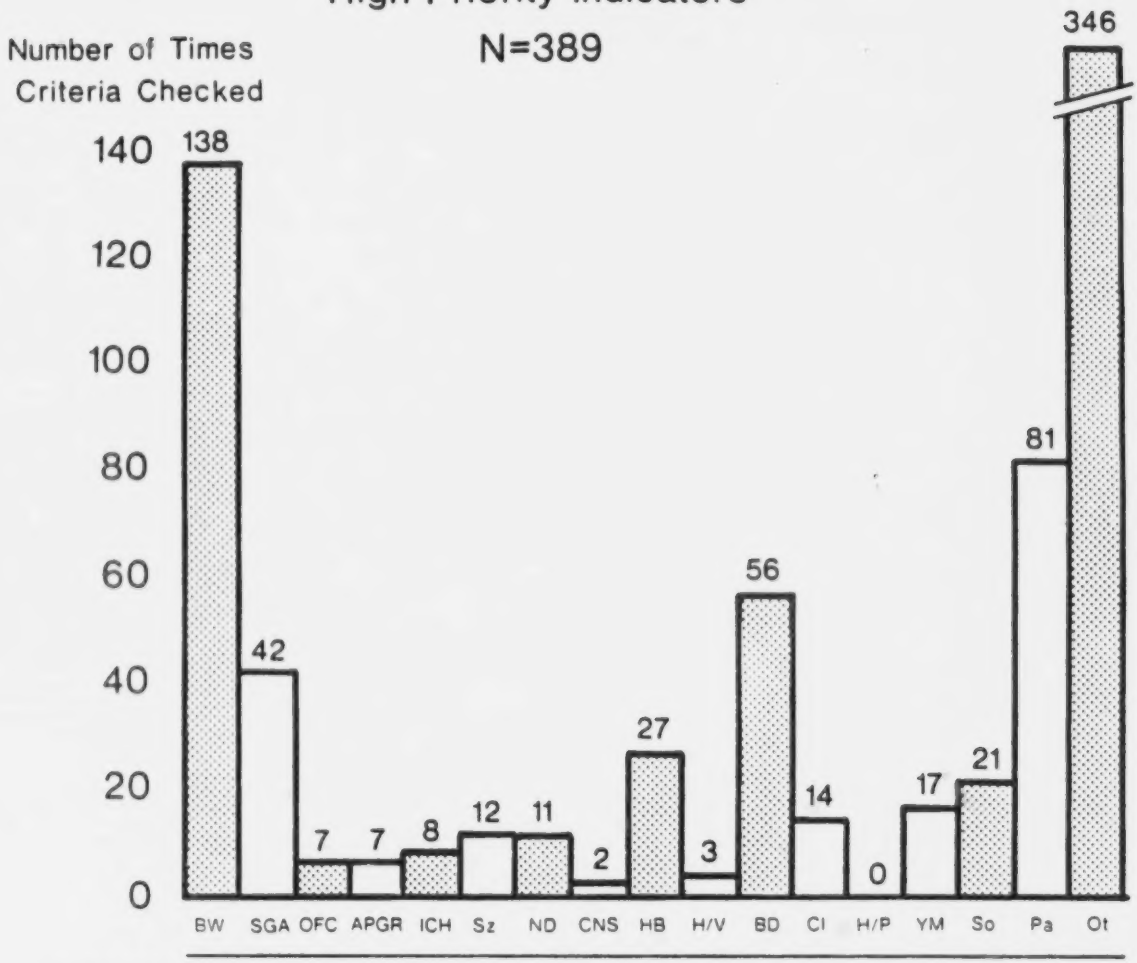
TABLE 2
WHATCOM COUNTY
INDICATORS OF HIGH PRIORITY

Birthweight less than 2500 grams:	138
Small for gestational age:	42
Occipital-Frontal Circumference less than ten percent:	7
Low APGAR (less than four at five minutes):	7
Intracranial Hemmorhage:	8
Seizures:	12
Neurological Disorders:	11
Central Nervous System Infection:	2
High Bilirubin (Greater than 20):	27
Hearing impairment:	1
Visual impairment:	2
Major Birth Defect*	56
Chromosome:	2
Musculoskeletal:	9
Cleft lip/palate:	6
Major gastrointestinal:	11
Cardiac Anomalies:	21
Central Nervous System:	2
Other:	8
Congenital Infection:	14
Hypothyroid:	0
PKU:	0
Mother less than 15 years of age:	17
Social concerns:	21
Parenting:	81
Other*:	346
Respiratory:	74
Infectious/Inflamatory:	35
Prematurity (< 37 weeks)	100
Other:	171

*Note: One infant may have more than one "major birth defect" and/or "other" problem.

Figure 4:

HPIT Project: Whatcom County
Frequency Distribution of
High Priority Indicators
N=389



Criteria:

BW: Birthweight < 2500 grams

SGA: Small for Gestational Age

OFC: Head Circumference

APGR: APGAR 4 at 5 minutes

ICH: Intracranial Hemmorhage

Sz: Seizures

ND: Neurological Disorders

CNS: Central Nervous System

HB: High Bilirubin 20 mg%

H/V: Hearing/Visual Impairment

BD: Major Birth Defect

CI: Congenital Infection

H/P: Hypothyroid/ PKU

YM: Young Mother ≤ 15 years

So: Social

Pa: Parenting Risk

Ot: Other

Health and Developmental Problems of High Priority Infants:

Two hundred and nine of 267 infants enrolled into the tracking system in Whatcom County have reached the first tracking period (three months). Of these 267 infants, 189 infants have reached the six month tracking period, 114 have reached the 12 month tracking period, 70 have reached the 18 month tracking period, 39 have reached the 24 month tracking period and the first 7 infants have reached the 36 month tracking period. Please keep in mind that information on one tracking period is not independent of information for the other time periods.

The health and development status of infants tracked through the Whatcom County Health Department at three months, six months, twelve months, eighteen months, and twenty-four months is summarized in the following report. A descriptive report of the seven thirty-six month old cases is reported. Data analysis for the thirty-six month old group is not reported due to the small number of cases.

Three Months:

Receiving Care: Two hundred and nine high priority infants were over three months of age at the time of the data analysis. Of the 209 infants with completed forms for this tracking period, 183 infants (88 percent) were still receiving care by their primary health care identified at birth, and eight infants were receiving care after being referred to a new primary health care provider. This indicate that 91 percent of the high priority infants tracked to three months remained in follow-up care. The reasons for the remaining 16 infants not receiving care from their original primary health care provider are as follows:

- Unable to locate:	1 infant
- Family Moved Out of the County:	6 infants
- Infant Receiving Only Acute Care. No Well Child Care:	2 infants
- Unknown reason:	9 infants
	18 infants

Health Status:

One hundred and ninety-nine high priority infants tracked through three months had information recorded regarding their current health status. One hundred and thirty (65 percent) of these infants had reportedly "normal health." Sixty-nine infants (35 percent) had one or more significant health concerns at three months.

The significant health concerns reported at this tracking period are represented in TABLE 3.

TABLE 3
HPIT: 3 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N=69)

Concern	Frequency
Central Nervous System:	16
Pulmonary:	11
Cardiac:	15
Renal:	5
Gastrointestinal:	24
Growth Disorders:	10
Failure to Thrive:	6
* Abnormal Head Circumference:	5
Malformation or Syndrome:	10
Socio-Medical:	15
Other:	15

*as indicated by an OFC < 3rd percentile or greater than the 97th percentile

Developmental Status:

Developmental status was reported for 176 cases. Questionable or abnormal developmental status was reported for 24 infants (14 percent) of the cases. Eighty-six percent (152) had reportedly "normal" development.

Six Months

Receiving care: One hundred and eighty-nine infants have completed forms for the six month tracking period. Of this group, 174 infants were documented as still receiving care from their primary care provider (92 percent). The remaining fifteen infants (8 percent) were not receiving follow-up care from their original primary health care provider for the following reasons:

- Deceased:	2 infants
- Moved Out of the County:	3 infants
- Acute Care Only/No Well Child Care:	2 infants
- Unknown/Other:	5 infants
- Referred to Another Provider:	3 infants
	15 infants

Health Status

Information regarding health status was available for one hundred and sixty-eight infants. One hundred twenty-eight infants tracked through the six month period have reported "normal" health (71 percent). Fifty-two infants (29 percent) tracked to this period have one or more significant health concerns. The reported concerns are depicted in TABLE 4.

TABLE 4
HPIT: 6 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N=52)

Concern	Frequency
Central Nervous System:	21
Pulmonary:	11
Cardiac:	11
Renal:	6
Gastrointestinal:	15
Growth Disorders:	6
Failure to Thrive:	2
* Abnormal Head Circumference:	2
Malformation or Syndrome:	10
Socio-Medical:	11
Other:	14

*as indicated by an OFC < 3rd percentile or > 97th percentile

Developmental Status

One hundred and sixth-three cases reported physician ratings of developmental status. One hundred and thirty-nine infants (85 percent) had reported "normal" development. Twenty-four infants (15 percent) were classified as having questionable/abnormal development at six months.

Twelve Months

Receiving care: One hundred and fourteen infants have completed tracking forms through the twelve month period in Whatcom County. Of these 114 infants, 106 (93 percent) continue to receive documented health care by their private health care provider. The remaining eight infants (7 percent) are not receiving care from their original primary health care provider for the following reasons.

- Moved From the County:	3 infants
- Receiving Only Acute Care/No Well Child Care:	1 infant
- Unknown Reason:	1 infant
- Can't Locate	2 infants
- Referral to another provider	1 infant
	8 infants

Health Status

Health status information was reported for one hundred and eleven infants. Seventy-five infants tracked through the 12 month period have recorded "normal" health (68 percent). Thirty-six infants have one or more health concerns (32 percent). The health concerns recorded are reported in TABLE 5.

TABLE 5
HPIT: 12 MONTH TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N=36)

Concern	Frequency
Central Nervous System:	9
Pulmonary:	9
Cardiac:	9
Renal:	2
Gastrointestinal:	6
Growth Disorders:	10
Failure to Thrive:	6
* Abnormal Head Circumference:	4
Malformation or Syndrome:	4
Socio-Medical:	4
Other:	12

(as indicated by an OFC < 3rd percentile or > 97th percentile

Developmental Status

Physician ratings of developmental status were available for one hundred and two cases. Eighty-one infants (79 percent) reportedly had "normal" development. Twenty-one infants (21 percent) had reportedly questionable/abnormal development at 12 months.

Eighteen Months

Receiving care. Seventy infants have completed 18 month tracking forms for Whatcom County. Sixty-three (90 percent) of these infants are receiving documented ongoing health care. The reasons for the remaining seven infants (10 percent) not receiving care from their original primary care provider are as follows:

- Moved From the County:	2 infants
- Receiving Only Acute Care/No Well Child Care:	2 infant
- Unknown Reason:	2 infants
- Late for Check-Up	1 infant
	7 infants

Health Status

Thirty-five infants (53 percent) with completed 18 month tracking forms had reportedly "normal health." Thirty-one infants (44 percent) had one or more significant health concerns. These concerns are summarized in TABLE 5.

TABLE 6
HPIT: 18 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N=31)

Concern	Frequency
Central Nervous System:	8
Pulmonary:	11
Cardiac:	6
Renal:	3
Gastrointestinal:	6
Growth Disorders:	5
Failure to Thrive:	3
* Abnormal Head Circumference:	4
Malformation or Syndrome:	5
Socio-Medical:	3
Other:	9

*as indicated by an OFC < 3rd percentile or > 90th percentile

Developmental status

Sixty-two cases reported developmental status at 18 months. Seventy-seven percent (48 infants) were "normal." Twenty-three percent (14 infants) were reported to have questionable/abnormal development.

Twenty-four Months

Receiving care. Thirty-nine infants have completed 24 month Tracking Forms from Whatcom County. Thirty-two infants (82 percent) were reported to be still receiving ongoing health care. In the seven cases (18 percent) not receiving care from their original primary care provider for the following reasons:

Don't Know Reason/Unknown	3 infants
Moved	1 infant
Referred to another provider	2 infants
Late for Check-Up	1 infant
	7 infants

*It is anticipated that the health and developmental status of those infants referred toanother health care provider will be obtained through follow up by the Whatcom County HPIT program.

Health Status

Health status was reported for thirty-three cases. Twenty-one infants (64 percent) had reportedly "normal" health at this tracking period. Twelve infants (36 percent) had one or more significant health concerns. The reported concerns are summarized in TABLE 6.

TABLE 7
HPIT: 24 MONTHS TRACKING FORMS
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N=12)

Concern	Frequency
Central Nervous System:	4
Pulmonary:	3
Cardiac:	3
Renal:	1
Gastrointestinal:	0
Growth Disorders:	1
Failure to Thrive:	0
* Abnormal Head Circumference:	1
Malformation or Syndrome:	3
Socio-Medical:	2
Other:	3

*as indicated by an OFC < 3rd percentile or > 97th percentile

Developmental Status

Developmental information was available for twenty-nine cases. Seventy-nine percent (23 infants) had reportedly "normal" development. Abnormal/Questionable development was reported for six infants (21 percent).

36 Months

Receiving care: Seven infants have now reached the 36 month tracking period in Whatcom County. These seven infants represent the first sample of high priority infants to have been identified and tracked for a complete three year period in Whatcom County. While this initial group is too small to yield significant inferential statistical information, descriptive statistics for this sample are included. All seven infants were reported as still receiving ongoing health care (100 percent).

Health Status

Three infants (43 percent) had reportedly "normal" health status. Four infants (57 percent) had one or more significant health concerns noted on the 36 month tracking form. These concerns are summarized in TABLE 8.

Developmental Status

Four infants (57 percent) had Questionnaire/Abnormal development at 36 months. The remaining three infants (43 percent) were reported as "normal" at this tracking period.

TABLE 8
HPIT: 36 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N=4)

Concern	Frequency
Central Nervous System:	1
Pulmonary:	1
Cardiac:	0
Renal:	0
Gastrointestinal:	1
Growth Disorders:	0
Failure to Thrive:	0
* Abnormal Head Circumference:	0
Malformation or Syndrome:	0
Socio-Medical:	1
Other:	0

*as indicated by an OFC < 3rd percentile or > 97th percentile

*Because of the small numbers of forms completed for the 24 month and 36 month tracking periods descriptive statistics only will be reported.

A comparison of the health and developmental status for all six tracking periods in Whatcom County is illustrated in TABLE 9.

Table 9

HPIT Project

Comparison of Health and Developmental Status in Whatcom County

Tracking period	Health		Development	
	Normal	Abnormal*	Normal	Questionable/ Abnormal
3 Months	65%	35%	86%	14%
6 Months	71%	29%	85%	15%
12 Months	68%	32%	79%	21%
18 Months	53%	47%	77%	23%
24 Months	64%	36%	79%	21%
36 Months	43%	57%	43%	57%

*Abnormal health is indicated by the reporting of one or more significant health concerns

Continuity of Care

The Whatcom County High Priority Infant Tracking Project has been successful in maintaining greater than 90% of the high priority infants identified in ongoing health care. Table 10 illustrates the continuity of care at each tracking period.

TABLE 10
HPIT: WHATCOM COUNTY
CONTINUITY OF CARE

TRACKING PERIOD	IN CARE	NOT IN CARE/Unspecified
3 MONTHS	91%	9%
6 MONTHS	92%	8%
12 MONTHS	93%	7%
18 MONTHS	90%	10%
*24 MONTHS	82%	18%
*36 MONTHS	100%	0%

*Limited reporting available for this tracking period.

Use of Community Services

Each tracking form sent to the primary care providers of high priority infants asked what kinds of community services were being utilized by the infants. This question was asked as a way to evaluate the number and type of services used, and as a way to plan for services in the future for these infants. All high priority infants enrolled into the tracking system are followed by the Whatcom County Health Depatment. However, this service was only recorded on less than 40 percent of the tracking forms.

Consultation with other professionals, clinics or physican was the most commonly reported community service. Due to the extremely small percentage of tracking forms which reported this information, no generalization regarding the use of community services can be made.

Table 11

HPIT Project

Reported Use of Community Services in Whatcom County

Tracking Periods	SERVICES						
	Consult.	WIC	Infant Stim. Interv. Prog.	CPS	Public Health Dept.	Other	Not Reported
3 months N=209	18	9	2	2	19	12	153
6 months N=189	27	7	3	1	18	11	131
12 months N=114	14	7	4	1	8	1	85
18 months N=70	2	0	7	4	3	2	49
24 months N=139	9	0	1	2	2	16	16
36 months N=7	0	0	1	1	0	2	0

THURSTON COUNTY

Thurston County has now participated one year and ten months in the pilot phase of the High Priority Infant Tracking Project. Two hundred and forty-nine infants residing in Thurston County have been identified as "high priority." Of these 249 infants 230 infants (93 percent) have been successfully enrolled into the tracking system. The remaining infants were not enrolled due to the following reasons:

- Physician Refusal — 4 infants
- Parental Refusal: — 2 infants
- Adopted: — 1 infants
- No Parent Signature: — 9 infants
- Blank/No Reason Given — 3 infants

Identifying Hospitals

The infants in the Thurston County Pilot Project are primarily identified at five hospitals known to care for Thurston County infants. These hospitals include Children's Orthopedic Hospital, Seattle, Washington; University Hospital, Seattle, Washington; Tacoma General Hospital, Tacoma, Washington; Madigan Army Medical Center, Tacoma, Washington; and St. Peter's Hospital, Olympia, Washington. Additionaly, infants missed as high priority during their hospitalization, or born outside of the hospital can be later identified either by the Public Health Department or the infant's private health care provider. Infants can be identified at any time during the first thirty days of life through a physician's request, home visit by a community health nurse, or a well child visit. The number of infants identified by each individual source is as follows:

Children's Orthopedic Hospital	7 infants	(3 percent)
University Hospital:	0 infants	(0 percent)
Tacoma General Hospital:	11 infants	(4 percent)
Madigan Army Medical Center:	17 infants	(7 percent)
St. Peter's Hospital:	178 infants	(72 percent)
Public Health Nurse/Physician:	36 infants	(14 percent)
Total	249 infants	

Number of Infants Identified Per Pilot Project Year

The pilot project for Thurston County began May 1, 1984. The number of infants identified during each project year is shown below.

- May 1, 1984 to December 31, 1984 — 75 infants (9.4 infants per month)
- January 1, 1985 to December 31, 1985 — 174 infants (14.5 infants per month)

* Statistics from Whatcom County indicate that 10-12% of all county births are "high priority" as identified by the High Priority Infant Tracking Project. If the same overall incidence rate occurs in Thurston County a projected number of 206 to 247 infants would be eligible for the HPIT project each year based on an annual birthrate of 2056 live births. The pilot project

in Thurston County appears to be successfully identifying greater than 80% of the eligible infants.

Within specific hospitals the incidence of "high priority" infants may vary dramatically. Gross projections of the expected numbers must be regarded as estimations only. Further research, chart review and follow-up is necessary to determine the actual incidence of "high priority" infants in Thurston County.

Tracking Process

Once an infant is identified as high priority, and both physician and parental agreement to enroll the infant into the tracking program is obtained, the infant is placed on the tracking schedule of three months, six months, twelve months, eighteen months, twenty-four months, and thirty-six months. All 230 infants with completed 'Identification Forms' and appropriate consents obtained have been placed on this schedule by the Thurston County Public Health Department, and are presently at different stages of the tracking program.

The numbers of completed forms for each Tracking Period is depicted in TABLE 12.

TABLE 12
HPIT PROJECT: THURSTON COUNTY
Completed Tracking Forms

Tracking Period	Number of Forms Completed
3 months	180
6 months	142
12 months	56
18 months	11
24 months	0
36 months	0

*The first HPIT Project enrollees in Thurston County are currently reaching the 18 month tracking period.

Characteristics of Thurston County High Priority Infants

Sex:

Fifty-eight percent (141 infants) of the "high priority" infants were male. Forty-two percent (101 infants) were female. The sex of the infant was not reported in seven cases. In Figure 5 the preponderance of males over females in relationship to the county distribution is shown.

Gestational Age

Thirty-one percent (76 infants) of the high priority infants identified in Thurston County were born before 37 weeks gestational age. Fifty-eight percent (145 infants) were born between 37 weeks and 45 (full term) weeks. Eleven percent (28 infants) of the cases did not report the gestational age. See Figure 6.

Birthweight

The mean or average birthweight for Thurston County high priority infants was 2885 grams (SD = 880 grams), with a range from 680 to 5520 grams. An illustraion of the average birthweight for Thurston County is found in Figure 7.

Figure 5:

Sex of High Priority Infants From Thurston County
Compared with Thurston County Births: 1984

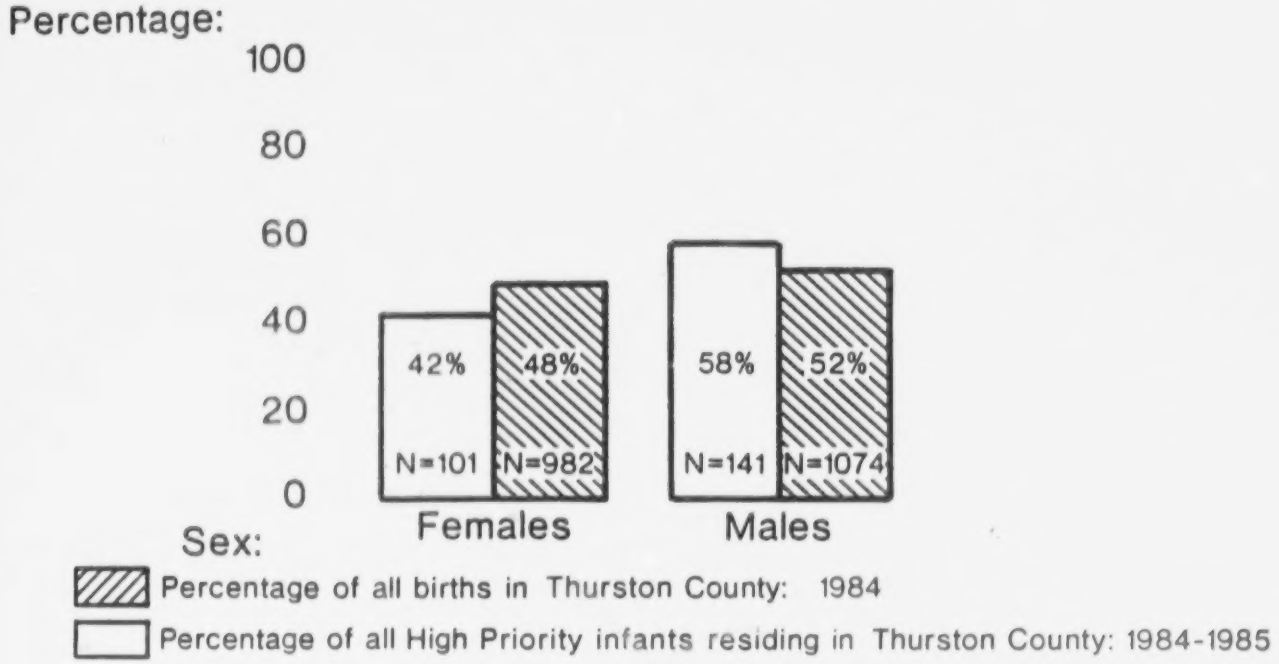


Figure 6:

Gestational Age of Thurston County
High Priority Infants
(N=249)

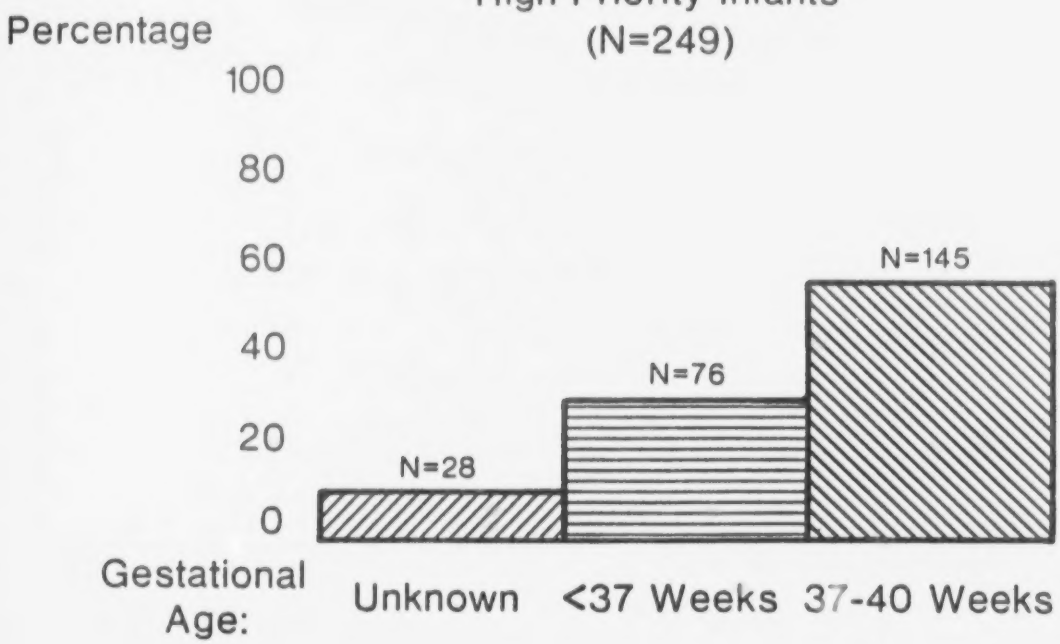
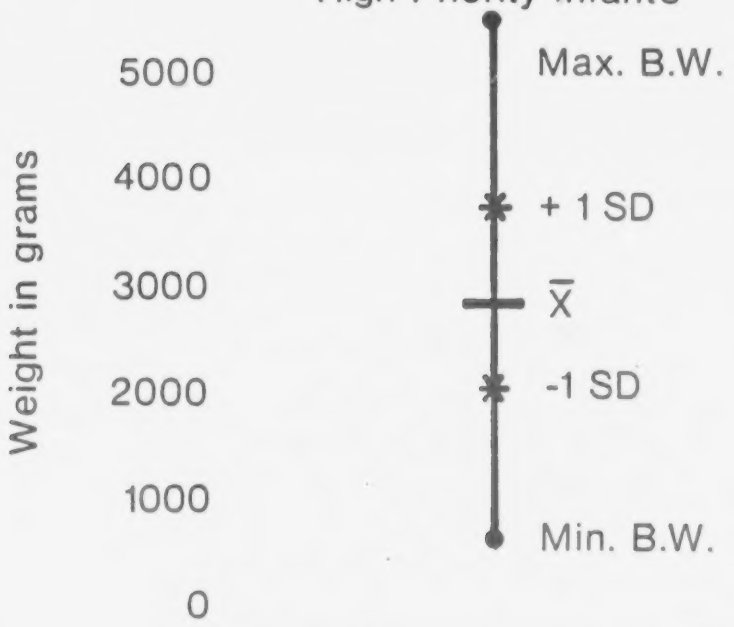


Figure 7:
Average Weight of Thurston County
High Priority Infants



(Standard Deviation equals 880 grams)

(Minimum weight = 680 grams; Maximum weight = 5520 grams)

Indicators of High Priority

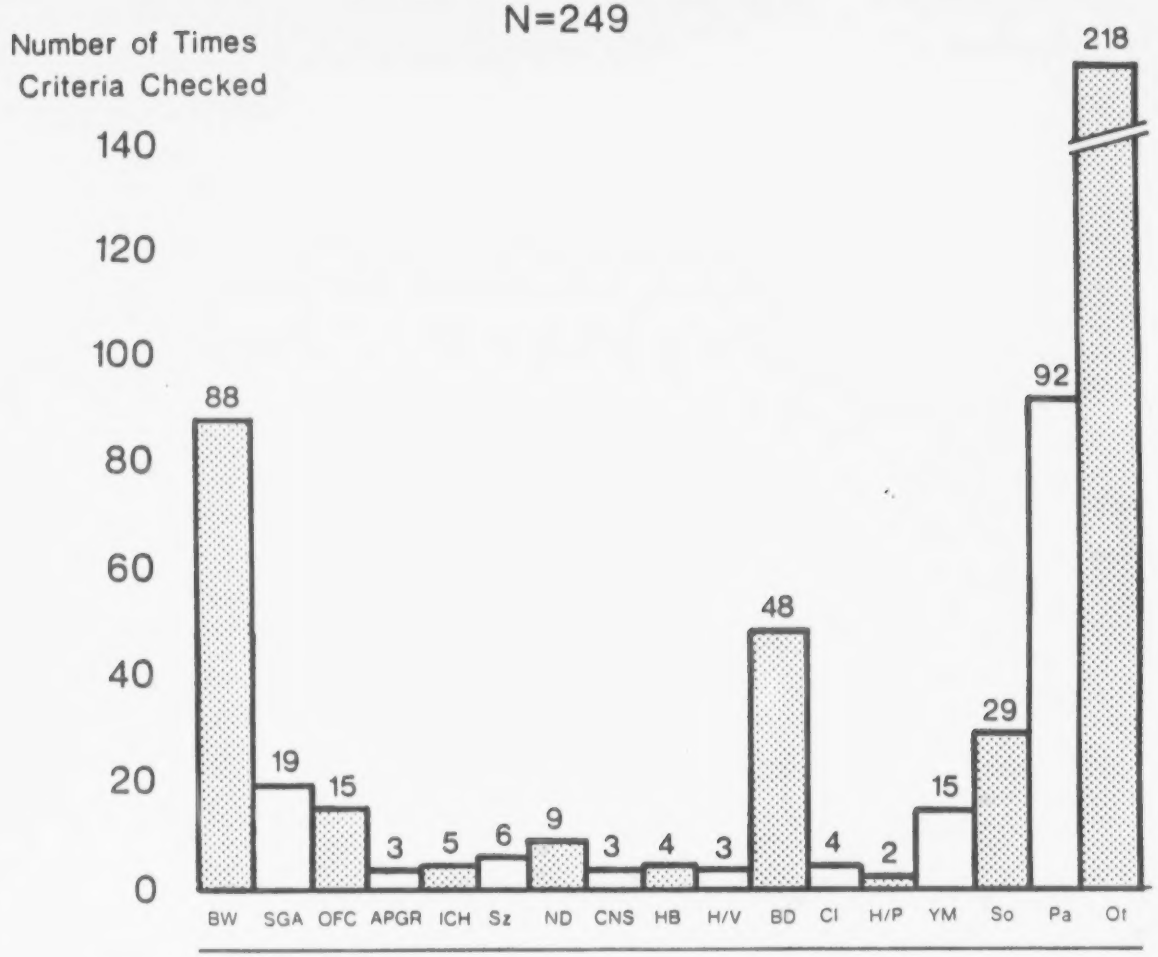
Each infant identified could have one or more of the 18 identifying criteria from the Identification Form. Figure 8 represents the number of times an identifying indicator was reported for the 249 infants with completed Identification Forms.

TABLE 13
HPIT PROJECT: Thurston County
High Priority Indicators

Birthweight less than 2500 grams:	88
Small for gestational age:	19
Occipital-Frontal Circumference less than ten percent:	15
Low APGAR (less than four at five minutes):	3
Intracranial Hemmorhage:	5
Seizures:	6
Neurological Disorders:	9
Central Nervous System Infection:	3
High Bilirubin (Greater than 20):	4
Hearing impairment:	1
Visual impairment:	2
Major Birth Defect*	48
Chromosome:	8
Musculoskeletal:	8
Cleft lip/palate:	4
Major gastrointestinal:	6
Cardiac Anomalies:	11
Major Renal:	5
Minor Birth Defects/Other:	4
Myleomeningocele:	1
Congenital Infection:	4
Hypothyroid:	2
PKU:	0
Mother less than 15 years of age:	15
Social concerns:	29
Parenting Risks:	92
Other*:	218

*note: An infant may have more than one major birth defect and/or other problems.

Figure 8:
HPIT Project: Thurston County
Frequency Distribution of
High Priority Indicators
N=249



Criteria:

BW: Birthweight <2500 grams

SGA: Small for Gestational Age

OFC: Head Circumference

APGR: APGAR 4 at 5 minutes

ICH: Intracranial Hemmorhage

Sz: Seizures

ND: Neurological Disorders

CNS: Central Nervous System

HB: High Bilirubin 20 mg%

H/V: Hearing/Visual Impairment

BD: Major Birth Defect

CI: Congenital Infection

H/P: Hypothyroid/ PKU

YM: Young Mother ≤15 years

So: Social

Pa: Parenting Risk

Ot: Other

TRACKING PHASE

Health and Developmental Problems of High Priority Infants in Thurston County

One hundred and eighty infants of the 249 infants identified as "high priority" in Thurston County have completed three months tracking forms. One hundred and forty-two infants have completed six months forms. Fifty-six infants have completed forms through the twelve months tracking period. The first group of infants to be enrolled in the High Priority Infant Tracking Project in Thurston County are currently reaching their eighteen months tracking period. The small number of infants at the eighteen months period is too small for analysis. Pooled statistics are reported for the three, six, and twelve month tracking periods. Note that the information obtained from the oldest enrollees is pooled with new information for each tracking period.

Three Months

Receiving Care

One hundred and eighty infants have completed three months tracking forms. Of these infants, one hundred sixty-one (89 percent) were still receiving documented health care. Nineteen infants (11 percent) were not under care with their original provider for the following reasons:

Dont' know/No reason given	10 infants
Moved	4 infants
Referred to another provider	3 infants
Deceased	1 infant
Unable to locate	1 infant
	19 infants

Health Status:

One hundred and sixty-seven infants had information regarding their health status. Of this subgroup, eighty-nine infants (53 percent) had reportedly "normal" health as reported by the primary care provider. Seventy-eight infants (47 percent) had one or more significant health concerns reported at this tracking period. These concerns are summarized in Table 14.

Table 14

HPIT: 3 Months Tracking Form
Significant Health Concerns (N = 78)
Thurston County

Central Nervous System	15
Pulmonary	13
Cardiac	9
Renal	6
Gastrointestinal	22
Growth Disorders	10
Failure to Thrive	9
* Abnormal Head Circumference	4
Malformation or Syndrome	18
Socio-Medical	13
Other	22

*as indicated by an OFC < 3rd percentile or > 97th percentile

Developmental Status:

One hundred and forty-six cases had physician ratings of development. Thirteen infants (9 percent) were reported as questionable/abnormal. One hundred thirty-three infants (91 percent) had reportedly "normal" development at three months.

Six Months:

Receiving Care

One hundred and forty-two infants have completed six months tracking forms. At this tracking period one hundred twenty-six (89 percent) were reported to be receiving ongoing health care. For the sixteen infants (11 percent) not receiving care from their original provider the following reasons were cited:

Dont' know/No reason given	8 infants
Referred to another MD	4 infants
Moved	2 infants
Unable to locate	2 infants
	16 infants

Health Status:

Health Status information was available for one hundred and thirty-four infants. For this subgroup, eighty-four infants (63 percent) had reportedly "normal" health. Fifty infants (37 percent) had one or more significant health concerns reported at the six months tracking period. A summary of the reported health concerns appears in Table 15.

Table 15

HPIT: 6 Months Tracking Form
Significant Health Concerns (N = 50)
Thurston County

Central Nervous System	16
Pulmonary	7
Cardiac	8
Renal	3
Gastrointestinal	8
Growth Disorders	7
Failure to Thrive	6
* Abnormal Head Circumference	2
Malformation or Syndrome	16
Socio-Medical	7
Other	9

*as indicated by an OFC < 3rd percentile or > 97th percentile

Developmental Status

One hundred and four cases reported physician ratings of developmental status. Ten infants (10 percent) were rated as questionable/abnormal. Ninety-four infants (90 percent) were rated as having "normal" development at six months.

Twelve Months:

Receiving Care:

Fifty-six infants have completed tracking forms for the twelve months tracking period. Forty-three infants (77 percent) of these infants were still receiving documented ongoing health care. For the thirteen infants (23 percent) not with their original provider the following reasons were cited:

Dont' know/No reason given	6 infants
Unable to locate	3 infants
Referred to another provider	2 infants
Moved	1 infant
Acute care only	1 infant
	13 infants

Health Status

Health Status information was available for fifty-one infants. Of this subgroup, twenty-five infants (49 percent) had reportedly "normal" health. Twenty-six infants (51 percent) had one or more significant health concerns reported at this tracking period. A summary of these concerns is found in Table 16.

Table 16

HPIT: 12 Months Tracking Form
Significant Health Concerns (N = 26)
Thurston County

Central Nervous System	7
Pulmonary	6
Cardiac	1
Renal	2
Gastrointestinal	1
Growth Disorders	4
Failure to Thrive	3
* Abnormal Head Circumference	1
Malformation or Syndrome	5
Socio-Medical	3
Other	14

*as indicated by an OFC < 3rd percentile or > 97th percentile

Developmental Status

Thirty-nine cases reported physician ratings of developmental status at twelve months. Six infants (15 percent) were rated as questionable/ abnormal. Thirty-three infants (85 percent) were rated as normal.

A comparison of health and developmental status for Thurston County high priority infants at three tracking periods is illustrated in Table 17.

Table 17

HPIT Project

Comparison of Health and Developmental Status in Thurston County

Tracking period	Health		Development	
	Normal	Abnormal*	Normal	Abnormal
3 Months	53%	47%	91%	9%
6 Months	63%	37%	90%	10%
12 Months	49%	51%	85%	15%

*Abnormal health is indicated by the reporting of one or more significant health concerns

Continuity of Care:

The Thurston County High Priorty Infant Tracking Project has successfully maintained greater than 85 percent of the high priority infants in ongoing health care. Table 18 illustrates the continuity of care for Thurston County.

TABLE 18
HPIT: THURSTON COUNTY
CONTINUITY OF CARE

TRACKING PERIOD	IN CARE	NOT IN CARE/UNSPECIFIED
3 months	89%	11%
6 months	89%	11%
* 12 months	77%	23%

* Small number of infants at this tracking period may alter the actual percentages.

Use of Community Services:

All high priority infants enrolled into the tracking system are being followed by the Thurston County Health Department. Approximately 40 percent of the high priority infants in Thurston County are utilizing other community services besides the public health department and/or their private health care providers during the three, six, and 12 months tracking periods. Other services being utilized include referral to other physicians or clinics, the Women, Infant, and Children's Program (WIC), other state programs, and physical therapy. The numbers of high priority infants utilizing community services in Thurston County is illustrated in Table 19.

Table 19

HPIT Project

Reported Use of Community Services in Thurston County

	SERVICES						
Tracking Periods	Consult.	WIC	Infant Stim. Interv. Prog.	CPS	Public Health Services	Other	Not Reported
3 months N=180	7	46	0	0	116	29	8
6 months N=142	6	45	0	1	109	29	3
12 months N=56	1	21	1	0	43	5	1

A COMPARISON OF WHATCOM AND THURSTON COUNTY

A total of 638 high priority infants have been identified in Whatcom and Thurston County. Greater than 85 percent of the high priority infants identified in these two counties and enrolled into the tracking system have been successfully maintained in the health care system. The number of high priority infants receiving ongoing health care in Thurston and Whatcom Counties is illustrated in Table 20. In order to provide additional information on characteristics and outcomes of high priority infants enrolled into the tracking system, the 'Identification' and 'Tracking' forms were combined and analyzed.

Table 20

HPIT Project

Whatcom/Thurston Counties Continuity of Care

	In Documented Care		Not in Care/Unspecified	
	Whatcom	Thurston	Whatcom	Thurston
3 Months	91%	89%	9%	11%
6 Months	92%	89%	8%	11%
12 Months	93%	77%	7%	23%
18 Months	90%	——	10%	——
24 Months*	82%	——	18%	——
36 Months*	100%	——	0%	——

—— Insufficient data

*Limited reported for this tracking period

Multiple Criteria Versus Single Criteria

Two hundred fourteen (34 percent) were identified as high priority by presenting a single eligibility criteria. Four hundred twenty-four (66 percent) infants had more than one identifying criteria.

Table 21 illustrates the each high priority indicator, and the percentage of times it occurred alone and in combination with other indicators. Additionally, frequent combinations of high priority indicators are shown.

Table 21
HPIT Project
Whatcom/Thurston Counties
Frequency of High Priority Indicators

High Priority Indicator	N (alone)	N combined	% IN combination	Most Frequent other factor
Birthweight 2500 Grams (LBW)	32	194	86%	Prematurity (n=133) SGA (n=42) Soc/Env/Par (n=56) Other Prob (n=47) Respiratory (n=30) Maj Birth Def (n=18)
Birthweight Less than 10% (SGA) Small for Gestational Age	3	58	95%	LBW (n=42) Soc/Env/Par (n=26) Other Prob (n=19) Prematurity (n=12)
OFC Less than 10th percentile or Greater than 90th percentile	3	19	86%	Maj Birth Def (n=9) Other Prob (n=6) Low Birth Wt (n=5) Env/Soc/Par. (n=7)
Apgar 4 at 5 Minutes	1	9	90%	Low Birth Wt (n=5) Prematurity (n=4) Respiratory (n=5)
*Intracranial Hemorrhage (ICH)	0	13	100%	Prematurity (n=9) LBW (n=8) Seizures (n=6)
Seizures	5	13	72%	Neurological Abn (n=6) Respiratory (n=6) ICH (n=6) Other Problems (n=6)
Neurological Abnormality	1	19	95%	Respiratory (n=9) Other Problems (n=9) Maj Birth Def (n=8) Seizures (n=6)

High Priority Indicator	N (alone)	N combined	% IN combination	Most Frequent other factor
Hyperbilirubinemia (_ 20mg%)	19	12	39%	Other Problems (n=5) Respiratory (n=4) Prematurity (n=4) Parenting Risk (n=4)
Major Birth Defect	35	68	63%	Other Problem (n=20) Low Birth Wt (n=14) Prematurity (n=13) Respiratory (n=11) Parenting Risk (n=9)
*Hearing/Vision	0	86	100%	Low Birth Wt (n=5) Prematurity (n=4) Maj Birth Def (n=3)
Congenital Infections	4	14	77%	Other Prob (n=11) Prematurity (n=5) SGA (n=5)
Mother Less than 15 Years	9	22	71%	Env/Soc/Par. (n=21)
Environmental/Social/ Parenting	40	162	80%	Other Probs (n=65) Low Birth Wt (n=56) Prematurity (n=36) SGA (n=26) Maj Birth Def (n=17) Respiratory (n=16)
*Prematurity	0	160	100%	Low Birth Wt (n=133) Other Problems (n=37) Env/Soc/Par. (n=36) Maj Birth Def (n=17) SGA (n=12) ICH (n=9)
Respiratory	22	91	81%	Other Problem (n=47) Low Birth Wt (n=30) Prematurity (n=30) Maj Birth Def (n=17) Env/Soc/Par. (n=16)

Note: Factors occurring less than three times in combination are not tabled. Each case may have one or more factors listed.

*Indicates a high priority indicator occurring only as a combined condition.

Predictive Ability of Identifying Criteria

Ninety-seven infants have completed identification forms and 3, 6, and 12 months tracking forms which include information related to health and

developmental status. The predictive ability of each individual identification criteria was analyzed for this subgroup of High Priority Infants. The incidence of health and developmental problems for each tracking period is reported in Table 22. Relative risk was computed for each criteria only when the cell size was _ 5.

A significant relationship between major birth defects identified at birth and the incidence of ongoing health problems was noted. The interpretation of this table is dependent upon the recognition of the fact that a single indicator alone was used. Of all 638 infants only 35 infants (5 percent) were identified on the basis of a major birth defect.

TABLE 22

INCIDENCE OF HEALTH AND DEVELOPMENTAL PROBLEMS BY HIGH PRIORITY INDICATOR FOR WHATCOM AND THURSTON COUNTY

HIGH PRIORITY INDICATOR	PROPORTION WITH DEVELOPMENTAL PROBLEMS			PROPORTION WITH HEALTH PROBLEMS		
	3 Mths	6 Mths	12 Mths	3 Mths	6 Mths	12 Mths
BW 2500 gm	12%	12%	24%	31%	31%	36%
Ratio	5:42	5:42	10:42	13:42	13:42	15:42
Relative Risk	92	.64	1.4	84	93	1.07
SGA (10%ile)	15%	15%	23%	38%	23%	31%
Ratio	2:13	2:13	3:13	5:13	3:13	4:13
OFC 10%ile 90%ile	0%	100%	100%	100%	100%	100%
Ratio	0:1	1:1	1:1	1:1	1:1	1:1
APGAR 4	0%	0%	0%	0%	0%	0%
Ratio	0:0	0:0	0:0	0:0	0:0	0:0
ICH	0%	33%	33%	66%	66%	66%
Ratio	0:3	1:3	1:3	2:3	2:3	2:3
Seizures	33%	33%	33%	100%	66%	66%
Ratio	1:3	1:3	1:3	3:3	2:3	2:3
Clinical Imp. Neurological Dis.	44%	75%	75%	75%	75%	50%
Ratio	3:4	3:4	3:4	3:4	3:4	2:4
Acquired CNS Inf.	0%	0%	0%	0%	0%	0%
Ratio	0:1	0:1	0:1	0:1	0:1	0:1
Hyperbilirubinemia	0%	0%	0%	0%	0%	17%
Ratio	0:6	0:6	0:6	0:6	0:6	1:6
Susp. Hearing Abn.	0%	0%	0%	0%	0%	0%
Ratio	0:0	0:0	0:0	0:0	0:0	0:0
Susp. Visual Abn.	100%	100%	100%	100%	100%	100%
Ratio	1:1	1:1	1:1	1:1	1:1	1:1
Major Birth Def.[a]	31%	25%	31%	81%	81%	75%
Ratio	5:16	4:16	5:16	13:16	13:16	12:16
Relative Risk	3.5	1.82	1.8	3.3*	3.6*	2.8*
Cong. Infect.	0%	25%	25%	75%	25%	25%
Ratio	0:4	1:4	1:4	3:4	1:4	1:4

HIGH PRIORITY INDICATOR	PROPORTION WITH DEVELOPMENTAL PROBLEMS			PROPORTION WITH HEALTH PROBLEMS		
	3 Mths	6 Mths	12 Mths	3 Mths	6 Mths	12 Mths
Cong. Hypothyr.	0%	0%	0%	0%	0%	0%
Ratio	0:0	0:0	0:0	0:0	0:0	0:0
Mother 15 yrs	13%	0%	0%	13%	13%	25%
Ratio	1:8	0:8	0:8	1:8	1:8	2:8
Prematurity	8%	11%	30%	27%	31%	42%
Ratio	2:26	2:26	6:26	7:26	8:26	11:26
Relative Risk	---	---	1.24	.73	.94	1.3
Respiratory	13%	13%	19%	44%	31%	38%
Ratio	2:16	2:16	3:16	7:16	5:16	6:16
Relative Risk	---	---	---	1.3	0.9	1.1
Other Problems[b]	20%	27%	27%	50%	40%	40%
Ratio	6:30	8:30	8:30	15:30	12:30	12:30
Relative Risk	2.2	2.5	1.6	1.8	1.4	1.4

[a]Includes chromosome abnormalities, cleft lip/palate, major GI, major cardiac anomalies, musculoskeletal, and major renal defects.

[b]Includes endocrine, infectious-inflammatory, minor renal, prenatal risks, and other minor defects.

*Probability of Chi Square _.05

Note: Relative Risk not calculated if cell size 5, to reduce statistical error.

Predictive Ability of Multiple Identifying Criteria

The relationship between multiple identifying criteria and later health and developmental outcomes was explored. Table 23 illustrates this relationship for 97 cases with completed identification forms and 3, 6, and 12 month tracking forms. Infants who are identified as "high priority" by presenting more than one identifying criteria do appear to have a greater incidence of health and developmental problems. These data however, are not statistically significant, but do represent a trend.

Table 23

HPIT Project

Whatcom/Thurston Counties

Multiple vs Single High Priority Indicators

Number of High Priority Indicators	Incidence of Health Problems			Incidence of Developmental Problems		
	3 mo	6 mo	12 mo	3 mo	6 mo	12 mo
Single	27%	20%	20%	6%	10%	10%
Multiple	38%	38%	40%	15%	18%	24%
Relative Risks	1.4	1.9	2.0	2.3	1.8	2.4

Health Status at Tracking Periods Predictive of Developmental Problems:

The relationship between early health problems and developmental outcome was examined for 97 infants who had complete reporting of health and developmenta status at the 3, 6, and 12 month tracking periods.

Relative risk calculations and chi square analysis was used to examine these data. As depicted in TABLE 24, early health status is significantly related to developmental outcome. Witn the exception of one tracking period (Health at 3 months x Development 12 months), early health problems were a significant indicator of developmental problems at the same, or a future tracking period. The six month tracking period was demonstrated to be the most predictive period.

Table 24

HPIT Project

Prevalence of Developmental Problems With Health Problems at Three Months, Six Months, and Twelve Months for Whatcom and Thurston Counties

*Based on 97 cases with complete reporting

Health	Prevalence of Developmental Problems		
	3 months	6 months	12 months
3 Months Abnormal			
percentage	30%	30%	30%
relative risk	9.8*	3.8*	2.2
6 Months Abnormal			
percentage		45%	48%
relative risk		30.1*	8.0*
12 Months Abnormal			
percentage			44%
relative risk			7.0*

*Probability of corrected Chi Square < .05

The Status of 97 Infants with 3, 6, and 12 Month Tracking Forms:

Ninety-seven infants from Whatcom and Thurston counties have complete reporting of health and developmental status through the twelve month tracking period. This subgroup was utilized to longitudinally examine the sensitivity and specificity of each tracking period for identification of health and or developmental problems.

Health status at 3, 6, and 12 months is represented in TABLE 25. Abnormal health at three months was related to abnormal health at twelve months. A similar relationship was demonstrated between abnormal health at six months, and abnormal health at the twelve month tracking period. Both relationships were statistically significant. It should be noted that the six month tracking period appears to reduce the false positives and false negatives, as well as increasing the sensitivity and specificity.

Developmental Status

Developmental status at three months was not found to be significantly related to later developmental status at twelve months. As shown in Table 26 the six month tracking period appears to be a better indicator of later developmental problems. The six month tracking period was found to be statistically significant, and the number of false positives at this period was reduced.

Table 25
HPIT Project
Sensitivity and Specificity of Health Problems
N=97

Health Status	Abnormal Health Status at 12 Months	
Abnormal Health at 3 Months	Sensitivity	41% *
	Specificity	79%
	False Positives	39%
	False Negatives	22%
Abnormal Health at 6 Months	Sensitivity	68% *
	Specificity	87%
	False Positives	26%
	False Negatives	17%

*Probability of Corrected Chi Square < .05

NOTE: Abnormal health is indicated by the reporting of one or more significant health concerns.

Table 26
HPIT Project
Sensitivity and Specificity of Developmental Problems
N=97

Developmental Status	Developmental Status at 12 Months	
Abnormal Development at 3 Months	Sensitivity	26%
	Specificity	91%
	False Positives	58%
	False Negatives	16%
Abnormal Development at 6 Months	Sensitivity	53%*
	Specificity	94%
	False Positives	33%
	False Negatives	11%

*Probability of Corrected Chi Square < .05

High Priority Infants with Social-Environmental-Parenting Risk Factors

Two hundred two infants (32%) were identified as having environmental, social and/or parenting (ESP) risk. Separate analyses were done to determine continuity of care, use of community services, and later health and developmental status of the infants so identified.

One hundred four of the infants with ESP risk were from Whatcom County, representing 27% of high priority infants identified for that county. The remaining 98 were from Thurston County, representing 39% of infants identified for that county. The difference between the counties in the proportion of infants with environmental, social or parenting risk was statistically significant ($p = .0013$).

Continuity of Care:

One hundred sixty-four (81 percent) of the infants identified with ESP risk were enrolled in the tracking project. By comparison, 76% of infants without this risk factor were enrolled. The difference in enrollment between the two groups was not statistically significant, indicating that the ESP infants were equally likely to be enrolled as were the non-ESP infants.

Infants with ESP risk were slightly less likely than those with no ESP risk to receive ongoing health care, as indicated by the tracking forms at 3, 6 and 12 months. However, the difference between the two groups was statistically significant only for the 6 month tracking period. Table 27 illustrates continuity of care for infants with ESP risk and those with no ESP risk.

TABLE 27
HPIT: ENVIRONMENTAL, SOCIAL, PARENTING RISK
BY CONTINUITY OF CARE

Tracking Period	ESP	No ESP	ESP	No ESP
3 months	84%	88%	16%	12%
6 months*	85%	93%	15%	7%
12 months	82%	90%	18%	10%

*Statistically significant, p less than .02

Use of Community Services by Infants with Environmental, Parenting or Social Risk

Community service use was recorded on less than 40% of the tracking forms, making generalization impossible. However, the available data were looked at to assess wnether infants with ESP risk differed from those without ESP risk in the extent to which they used community services. For the cases for which utilization was recorded, infants with ESP risk used community services at least as extensively as did those with no ESP risk. ESP infants represented

about 32% of cases for which service utilization was recorded. The subgroup of ESP infants used 39% of public health nursing services and 55% of WIC service at the 3 month tracking period. Similar use was made at the 6 month tracking period. Although inconclusive, the data suggest that the ESP infants make appropriate use of community services.

Predictive Ability of Environmental, Social and Parenting Risk for Health and Development of Infants

Ninety-six infants had completed identification forms and 3, 6, and 12 month tracking forms which include information on health and developmental status. Of the 96 infants, 25 (26 percent) were identified as having ESP risk, 71 (74%) as having no ESP risk. The results of the analysis are reported in Table 28.

TABLE 28
PREVALENCE OF HEALTH AND DEVELOPMENTAL PROBLEMS
BY ENVIRONMENTAL, SOCIAL OR PARENTING RISK (N=96)

	Proportion with Developmental Problems			Proportion with Health Problems		
	3 mths	6 mths	12 mths	3 mths	6 mths	12 mths
ESP risk	8%	12%	20%	20%	24%	36%
Ratio	2:25	3:25	5:25	5:25	6:25	9:25
Rel. risk	*	*	1.02	.51	.68	1.07
No ESP risk	14%	17%	20%	39%	35%	34%
Ratio	10:71	12:71	14:71	28:71	25:71	24:71
Rel. risk	*	*	.99	1.97	1.47	.94

*Relative risk was not calculated for cells with less than 5.

As Table 28 indicates, infants identified as having ESP risk were no more likely to have health or developmental problems at 3, 6 or 12 months than were infants with no ESP risk. The reader should keep in mind that this analysis was based on a very small proportion (12 percent) of all infants with identified ESP risk, and further observation is warranted.

Multiple Identifying Criteria vs. Single Criteria

One hundred sixty-two (80 percent) of the infants identified as having environmental, social or parenting risk also had other high priority indicators. Other indicators identified most frequently were other minor proolems (n=65), low birth weight (n=56) and prematurity (n=36), as reported previously in Table 21.

Health Status at Tracking Periods and Developmental Outcomes

The relationship between early health problems and developmental outcome was examined separately for the 29 ESP infants with completed identification and 3, 6, and 12 month tracking forms. For that group, health status at 3 months and at 12 months was significantly related to developmental status at

12 months (p less than .03). Other health and developmental status relationships were not significant. The results of this analysis were quite different from the analysis of the larger sample of 97 infants, which found strong and significant relationships between health status and developmental outcomes at all tracking periods. The failure of the analysis of the ESP ifants to support the findings from the larger sample is almost certainly due to the small size of the ESP sample. This analysis should be repeated as more data become available.

Summary

Analysis of the data for infants with environmental, social or parenting risk indicated that group was not significantly different from the total group of high priority infants in continuity of care, use of community services, and later health and developmental status. Further analysis and comparison is warranted, as more data become available.

Discussion:

The High Priority Infant Tracking Project has successfully completed over three years of pilot study in Whatcom County and over eighteen months in Thurston County. During this period 638 infants have been successfully indentified as high priority.

Data collection from the Whatcom County and Thurston County - Pre-Pilot Studies, indicate that as many as 50 percent of the high priotity infants in a given county were lost to routine follow-up health care before their third birthday. The High Priority Infant Tracking Project has successfully maintained greater than 85 percent of the enrollees in ongoing health care and developmental surveillance.

Early identification of high priority infants who may require further evaluation, intervention or support services has been successfully demonstrated. Data analysis indicate that infants can be correctly identified as having a potentially ongong health concern at three months of age. Developmental concerns can be correctly identified at six months of age. Early recognition of the predictiveness of these early tracking stages for later health and developmental outcomes can facilitate the prompt follow up and referral for those infants with potential problems.

Systematic data collection regarding the use of local resources, incidence of disabilities, and the demographic characteristics of the high priority infant population has provided significant information for local and state health and education planners. In Thurston County the data collected from the High Priority Infant Tracking Project has documented the need for a neuromuscular center in that area.

In addition to specifically meeting the primary objectives of the program, other benefits of an organized systematic tracking system have become apparent. These additional benefits are summarized below.

Public health nurse referrals in both counties have increased dramatically since the implementation of the project. One year after implementation of HPIT, Maternal Child Health referrals in Thurston County rose twenty-seven percent. Two years after implementation MCH referrals from St. Joseph Hospital to the Bellingham-Whatcom Health District rose fifty-two percent. Public health personnel cite the HPIT project as a leading factor in accounting for this increase.

The liaison between community physicians, hospital personnel, and the public health departments has improved as a result of the HPIT project. In both counties, community health nurses and hospital nurses have reported improved cooperation and communication.

Hospital nursery staff have benefited from ongoing inservice provided by their contacts with the local community health nurse on an informal basis, and on a more formal basis through inservice provided by university, staff members. Hospital staff have become proficient in recognizing and referring infants who are at risk for developmental and/or medical problems. This increased sensitivity has led to increased referrals for other related services.

The liaison between the state Maternal and Child Health Services, the University of Washington, the public health departments, and the participating hospitals has improved.

These reported benefits are the outcome of the improved intra-agency, and inter-agency communication that has been significantly influenced by the HPIT project. The greatest benefit of the tracking project is in the benefit to the high priority infant and his family. A philosophy of preventive health care and continuity with a local health care provider will enhance the quality of care for the high priority infant and may alter the families perspective regarding health care as a priority for other children.

SUMMARY

The High Priority Infant Tracking Project has been successfully carried out for more than three years. Greater than 85 percent of the identified high priority infants enrolled into the tracking system have continued to receive ongoing health care.

- More high priority infants are male than female. Most high priority infants are born after 36 weeks gestation. This supports the importance of not using only "prematurity" as the only indicator for high priority.

- The most common identifying indicator continues to be low birthweight (less than 2500 grams).

- Health problems identified at any tracking period appear to be significantly related to developmental concerns at the same or future tracking periods.

- A majority of high priority infants had greater than one identifying indicator. Multiple criteria appear to increase the infant's risk for developing future health and/or developmental concerns, but the relationship between multiple criteria and future problems is not significant.

- Health problems identified at three and six months are significantly related to continuing health problems at 12 months.

- Developmental concerns identified at six months are significantly related to continued developmental problems at 12 months.

- The most common community service utilized by high priotity infants is the public health department. Other services include referral to physicians or clinics, supplemental food and income programs, and infant stimulation programs.

STATE

PATIENT DATA

CHILD'S NAME: _____ (last) _____ (first) _____ (middle)

DATE OF BIRTH: _____ GESTATION (weeks): _____ ( ) Male ( ) Female

Infant born in this hospital: ( ) Yes ( ) No. If no, hospital of birth: _____

MOTHER'S NAME: _____ (last) _____ (first) _____ (middle)

FATHER'S NAME: _____ (last) _____ (first) _____ (middle)

GUARDIAN, if any: _____ (last) _____ (first) _____ (relationship)

ADDRESS: _____ (street or route no.) _____ (town) TELEPHONE: _____

_____ (county) _____ (zip)

Name of persons other than parents who will know where child can be located:

1. _____ (name) _____ (address) _____ (telephone no.)

2. _____ (name) _____ (address) _____ (telephone no.)

HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)

( ) Birth weight ≤5 lbs. 8 oz. (≤2500 gms.)
( ) Birth weight ≤10th %tile for gestational age (SGA)
( ) Head Circumference (OFC) ≤10th %tile or ≥90th %tile for gestational age
( ) Apgar score less than 4 at 5 minutes
( ) Intracranial hemorrhage
( ) Seizures
( ) Clinical impression of neurological abnormality DESCRIBE: _____

BIRTH WEIGHT _____ gms.
____ lb. ____ oz.
OFC. ____ in./cms.
APGAR _____

( ) Acquired CNS infection (e.g., meningitis) DESCRIBE: _____

( ) Hyperbilirubinemia (≥20 mg%) mg% _____
( ) Suspected/confirmed hearing impairment
( ) Suspected/confirmed visual impairment
( ) Major birth defect or syndrome DESCRIBE _____

( ) Congenital fetal infection: ( ) toxoplasmosis ( ) rubella ( ) herpes ( ) cytomegalic virus ( ) syphilis
( ) Confirmed congenital hypothyroidism
( ) Confirmed PKU
( ) Mother 15 years of age or under
( ) Significant environmental, social, or parenting risk DESCRIBE: _____ AGE ____ yrs.

( ) Other problems: _____

FORM COMPLETED BY: _____ DATE: _____

I have reviewed the above information and believe it to be correct.

_____ DATE: _____
(Attending Physician Signature)

PARENT'S PERMISSION

I have had the "High Priority Infant Tracking Program" explained to me orally and in writing and agree to having my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information as indicated above to my child's health care provider and to the local health department where my child resides presently or in the future. I understand I can withdraw my child from this program at any time. My child's health provider is:

_____ (name of health provider)

_____ (address) (town) (state) (zip)

_____ (Witness' Signature) (Parent's Signature)

_____ (Date) (Date)

( ) Refused tracking system: _____

TIME RECORD FOR THIS PATIENT

HOSPITAL STAFF

TIME SPENT ON HPIT: Please check appropriate time spent in each activity.

IDENTIFICATION (eg. identifying infant; preparing forms and charts, etc.)
( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

PARENT CONTACT (eg. obtaining consent; explaining program, etc.)
( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

HEALTH DISCIPLINE CONTACTS (eg. communication with other staff relative to HPIT activities)
( ) None ( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

DPHS 13-570 (10-82) GS A-90

Appendix B

FORM SENT TO: _____ CASE NUMBER _____

HIGH PRIORITY INFANT TRACKING FORM OF WASHINGTON STATE

PATIENT DATA

CHILD'S NAME: _____ DATE OF BIRTH: _____

PARENT'S NAME: _____ TELEPHONE _____

ADDRESS: _____

(street or route number) (town) (county) (zip)

If different from above, please correct: _____

RETURN FORM TO

AGENCY: _____ ATTENTION: _____

(person requesting information)

ADDRESS: _____ TELEPHONE: _____

Check TRACKING CONTACT:( ) 3-4 mos.( ) 6-7 mos.( ) 12 mos.( ) 18 mos.( ) 24 mos.( ) 30 mos.( ) 36 mos.

TRACKING DATA

Is this child still receiving health care from you? ( ) Yes ( ) No

If no, indicate reason: ( ) Don't know ( ) Cannot locate ( ) Deceased

( ) Moved to: _____ (state or county)

( ) Referred to another physician: _____

Address: _____

( ) Other: _____

Please indicate:

I. HEALTH STATUS: ( ) Normal ( ) Other. If other, check **MAJOR** problems and specify as necessary below.

( ) A. CNS. ( ) Cerebral Palsy ( ) Seizures ( ) Hydrocephalus

( ) Structural defects, specify: _____

( ) Other: _____

( ) B. Pulmonary, specify: _____

( ) C. Cardiac, specify: _____

( ) D. Renal, specify: _____

( ) E. GI, specify: _____

( ) F. Growth Disorders: ( ) Failure to thrive

( ) Head Circumference (≤3rd %tile or ≥97th %tile)

( ) G. Malformation or syndromes, specify: _____

( ) H. Sociomedical: ( ) Child abuse/neglect ( ) Other, specify: _____

( ) I. Other, specify: _____

II. BEHAVORIAL/SENSORY DEVELOPMENT

A. Developmental Milestones — considering age (corrected for prematurity if any)

1. Personal-social: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
2. Fine motor: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
3. Gross motor: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
4. Language: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
5. Mental: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment

B. Vision: ( ) Normal ( ) Abnormal, specify: _____

C. Hearing: ( ) Normal ( ) Abnormal, specify: _____

D. Other, specify: _____

III. INTERVENTION SERVICES

A. With respect to the problems mentioned above, has the child and family received services from other community agencies during the past year?

( ) No ( ) Yes. If yes, specify type: _____

B. If no, why is the child not receiving these services? ( ) managing problems myself

( ) family refused ( ) appropriate services not available in community

Date last seen by you _____

TIME RECORD

FOR PRIMARY HEALTH CARE PROVIDER ONLY: Please check appropriate box indicating time spent in completing form.

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

CASE CLOSURE

FOR PHN ONLY:

Date of closure: _____ Reason: Moved out of ( ) state or ( ) county

( ) Parental permission withdrawn

( ) Cannot locate ( ) Deceased

TIME RECORD FOR THIS PATIENT

Time spent on HPIT: Please check appropriate time spent in activity

ADMINISTRATION (eg. developing file; sending tracking form, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

PARENT CONTACT (eg. activities related to tracking lost infant; follow-up, etc.)

( ) none ( ) 1-20 min. ( ) 31-60 min. ( ) 61-120 min. ( ) 2-3 hrs. ( ) 3-4 hrs.

( ) Other, please specify in hours _____

PRIMARY HEALTH CARE PROVIDER CONTACT (eg. communication relative to HPIT activities)

( ) none ( ) 1-10 min. ( ) 11-20 min. ( ) 21-31 min. ( ) 32-42 min. ( ) 43-53 min.

( ) 54-64 min. ( ) Other, please specify in hrs. _____

COPY TO: WHITE — HEALTH DEPARTMENT CANARY — HPIT PROJECT

DSHS 13-000 (3/80) 02 A 00

APPENDIX C

CASE HISTORIES

The following case histories are based on actual participants in the HPIT project. Names, and some minor details have been altered to protect the identity of the child and his or her family.

CASE #1 - "MINDY"

Mindy surprised her parents by being born two months early. As a result of her prematurity Mindy only weighed 900 grams at birth or about two pounds. She spent the first two months of her life at the Regional Perinatal Center in Seattle, Washington. In addition to these concerns, Mindy also suffered an intracranial hemmorhage, a common problem in prematurity. During her enrollment in the HPIT project she has been cared for and monitored by her family doctor in her local area. The tracking forms at three, and six months reflect her bumpy medical course. Problems at these early periods were related to prematurity, and gastrointestinal problems. In the early stages, Mindy's development was not of great concern. What was a concern were the hospital bills, and the resulting financial burden for her family. The Department of Social and Health Services, and the local health department visiting nursing services helped the family at this point financially, and supportively.

At the twelve month tracking period cerebral palsy was noted, with some associated delays in other areas, such as fine motor, and language. Intervention services included physical therapy, home visits from the public health department, and an infant stimulation program.

These techniques and coordinated services have been continued during the last two years. Mindy is now due to be inrolled in a local school district program for handicapped preschool children. In addition, a private therapist works with her in the family home.

CASE #2 - "KYLE"

Kyle was born at 42 weeks gestational age. He weighed over eight pounds at birth. Shortly after he was born, Kyle was transferred from his local hospital to a regional perinatal center. During Dyle's two week stay in the hospital a congenital heart condition was diagnosed. Kyle's heart specialist requested that the family return to the regional center for monitoring of his heart condition, and possible surgery.

When the public Health Department attempted to contact Kyle's local primary care provider at the three month tracking period, it was returned to them blank. Further follow up indicated that Kyle had not seen his local care provider for any well child visits since the time of his discharge from the hospital. Through the efforts of the community health nurse and the High Priority Infant Tracking Project Liaison in the regional perinatal center the family was contacted in person. The need to maintain contact with a local primary health care provider was discussed. While Kyle was not a "well baby", the family was confused regarding the need for ongoing visits with their local provider, also, they were under the impression that the heart specialist could

"handle it all." The family has subsequently made contact with their local physician, and the twlve month tracking form is due any day.

CASE #3 - "DANNI"

Danni will be two yers old next month, her mother will be eighteen. When Danni was born in her local hospital her mother was sixteen, single and had not received any pre-natal care until late in her pregnancy.

In addition to the social-environmental problems, Danni was born a month premature, and weighed less than 2500 grams (5 lbs., 8 oz.) at birth. Respiratory problems were also noted on her Identification Form. Danni is a child that is considered "doubly vulnerable" due to the medical and social risk factors.

Danni's respiratory problems continued, and pertussis was noted on her three month tracking form. No developmental concerns were noted.

At the six month tracking period Danni's primary care provider reported that Danni had not been seen for a well child check up since the age of three months. Follow-up at this point was initiated by the community health nurse responsible for the HPIT project.

The community health nurse made a home visit to Danni and her mother because they had no telephone. The community health nurse facilitated a visit to the local well child clinic, enrollment in a supplemental food program, and renewed contact with a primary care provider in the community. Danni's mother had decided to change physicians after the three month check up. She did not notify her previous physician, or request a transfer of records. Danni's care provider was not aware the family had transferred care to another physician.

Danni was seen for her one year old check up. The twelve month tracking form notes that the respiratory problem and chronit otitis media are ongoing concerns. Two new problems are noted on the form; a heart murmur, and eczema. No developmental concerns were noted.

Unfortunately, Danni left the tracking program at this point. She moved out of the state to a small town in the rural south. We do not know if Danni has been referred to a cardiologist, or what developmental concerns will arise later.

CASE #4 - "BILLY"

Billy is three years old. He has been closely monitored by many agencies since he was born. Billy's identification form notes only two high priority conditions. Some children have as many as five or six. Billy was born one month premature, and weighed less than 2500 grams (5 lbs. 8 oz.) at birth.

The High Priority Infant Tracking Project has monitored Billy, and a tracking form is on file for the three, six, twelve, eighteen, twenty-four and thirty-six month period.

Billy's form were completed by his local primary care provider who saw him for acute care. Billy's well child care was provided through the local well

child clinic at the health department, due to a lack of family financial resources.

Billy's early problems may seem "minor" but Billy's continued problem demonstrate that he is a child "at risk." Billy was suspected of hydrocephalus, but this problem resolved itself. Other problems cropped up; growth problems, lags in motor development, and communication skills development. These problems have been carefully monitored. Improvement has been noted, but a referral for a complete evaluation has been initiated.

Billy is not "out of the woods" yet. His early "minor" problems have been related to later health and developmental problems. Billy's parents are concerned, and request "check-up" visits regularly with the well child staff.

Billy has "graduated" from the tracking program but he still remains "at risk."

HIGH PRIORITY INFANT TRACKING PROJECT

COST ANALYSIS REPORT

FISCAL YEAR

07-01-84 TO 06-30-85

Patricia J. Biro, M.Ed., Coordinator
High Priority Infant Tracking Project
CDMRC-446,WJ-10
University of Washington
Seattle, WA

ACKNOWLEDGEMENTS

This project is supported by the State of Washington Maternal Child Health Services. The author wishes to thank the participating hospitals, local health department staff, and the participating staff at the University of Washington for their assistance in the preparation of this report.

INTRODUCTION

In October, 1982 the Washington State Maternal and Child Health Services, in coordination with the University of Washington, implemented the High Priority Infant Tracking Project (HPIT) as a pilot project in Whatcom County, Washington. To evaluate the effectiveness of the tracking system, Thurston County, Washington was added to the pilot project as a matched county in May, 1984. The primary objectives of the project are as follows:

1. To help parents keep their child under the care of a primary physician.

2. To promote early identification of infants requiring further evaluation, or services.

3. To assist in planning for the health and educational needs of the children of Washington State.

The HPIT project is initiated by first identifying high priority infants according to "high priority" indicators listed on the IDENTIFICATION FORM (see Appendix A). Infants may be identified using one or more of the eighteen criteria including medical, social, parenting, or environmental risk factors. The IDENTIFICATION FORM is then completed, noting the risk factors identified, and consent is obtained from the infant's parents and the primary health care provider. A copy of this form is then sent to the public health department, and enrollment into the tracking system is completed.

A TRACKING FORM (see Appendix B) is sent to the infant's primary care provider at three months, six months, twelve months, eighteen months, twenty-four months, and thirty-six months. This form requests information regarding the infant's health and developmental status, use of community services, and whether or not the infant is still receiving ongoing health care. If the health care provider indicates the infant is not receiving care, the community health nurse attempts to locate the family and reconnect them with the health care system. Follow-up activities by the community health nurse may include written communication with the family and the primary care provider, telephone calls and home visits.

As a component of the EVALUATION PHASE of the High Priority Infant Tracking Project the following Cost Analysis Report was completed. It covers the period from 7-1-84 to 6-30-85. This report attempts to identify the costs involved in the identification and tracking of high priority infants and the benefits of the HPIT Project for the community.

OVERVIEW OF COST CATEGORIES

Administration and coordination of the High Priority Infant Tracking Project occurs at three distinct levels (see Figure 1). At the initial level, financial support, project administration, and clerical support are provided at the state level through Maternal/Child Health Services. Coordination at the next level occurs at the University of Washington, where primary responsibilites include data collection, data analysis, coordination and support to the two participating counties. The day to day activities of the project are carried out by personnel at the two participating health departments, in coordination with the local hospitals.

The following areas and cost categories were considered in the development of this report:

ADMINISTRATION

SECRETARIAL AND CLERICAL SUPPORT SERVICES

NURSING

CONSULTATION

PRINTING

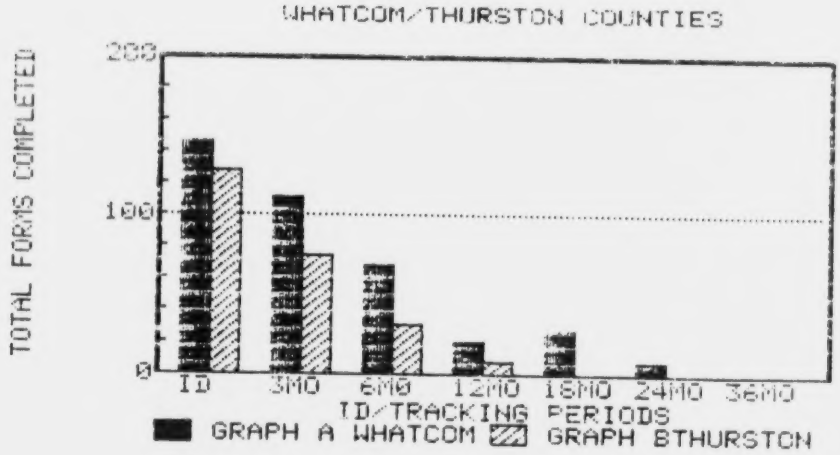
MAILING

COMPUTER/ DATA ANALYSIS

During the time period examined approximately four hundred thirty-five infants participated in the tracking project. Whatcom county infants represented 270 of the total sample (62%). The remaining 165 infants (38%) were residents of Thurston County. A total of 588 forms were completed and analyzed during this period. The distribution of completed forms for each county is represented in Figure 2.

FIGURE 2
HPIT PROJECT

DISTRIBUTION OF FORMS



ACTUAL COSTS

Washington State Maternal/ Child Health Services

Administrative activites carried out by project staff at the state level include consultation services, bulk mailing of written reports and communication,printing of forms used in the HPIT Project, and clerical support services for the project. State nursing consultation services were provided on site in Whatcom and Thurston Counties. These services were delegated to the University of Washington staff in 1985 when the technical assistant position was increased to 1.0 F.T.E. Additionally, meetings and communication with the HPIT Project State Advisory Committee is coordinated through the state Maternal/Child Health Services Division.

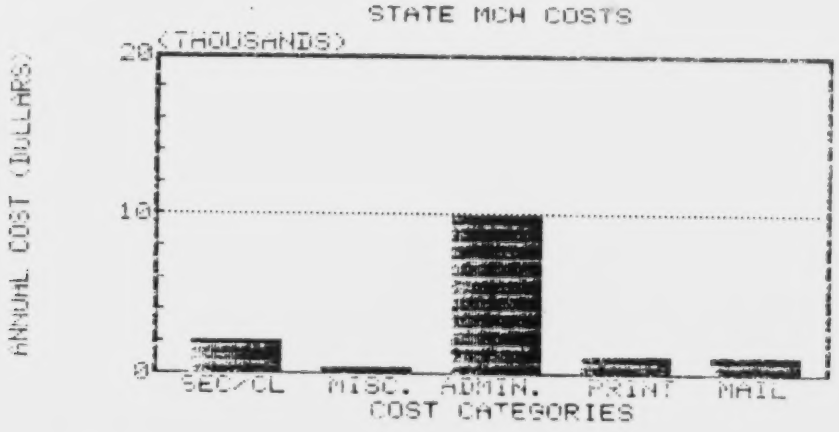
The following costs were incurred by the State of Washington Maternal/Child Health Services during the period from 7-1-84 to 6-30-85. These costs reflect the amount of time, as represented as a full time equivalent person, (F.T.E.), and the projected dollar amount of that time, as well as actual printing and mailing costs. These costs are represented in TABLE 2 . Figure 3 graphically displays these data

TABLE 2

HPIT PROJECT COSTS
WASHINGTON STATE MATERNAL/CHILD HEALTH SERVICES

COST CATEGORY	F.T.E.*		AMOUNT
Administration	.05	Director:	$1,500.00
	.30	Nurse Consultant	$8,400.00
Secretarial and Clerical Support	.20		$2,000.00
Printing			$1,200.00
Mailing			$1,200.00
Misc.		travel, mileage	$ 176.50
		Advisory Meetings	$ 150.00
		TOTAL	$14,626.50

FIGURE 3
HPIT PROJECT COSTS



University of Washington

HPIT Project activites at the Univeraity of Washington include data collection from Whatcom and Thurston Counties, data analysis, and interpretation of the data. Summary reports of the data analysis are written annually for the overall project, and bi-annually for each county. In addition, other written materials, such as the HPIT Project Procedures Manual are developed at the University of Washington. In coordination with the MCH State nursing consultants project consultation and chart review assistance in Whatcom and Thurston Counties was provided by HPIT Project staff at this level. Project evaluation activities,such as the Thurston County Pre-Pilot Study also occur at this level.

The costs incurred at the Univeraity of Washington in administration of the High Priority Infant Tracking Project during the period examined from 7-1-84 to 6-30-85 are represented in TABLE 3. Project personnel costs are represented as a portion of a full time equivalent (F.T.E.). Figure 4 displays this information in graph form.

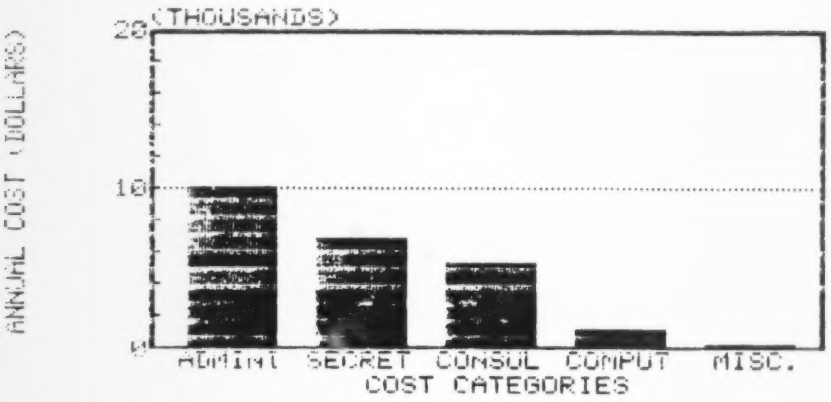
TABLE 3

HPIT PROJECT COSTS
UNIVERSITY OF WASHINGTON

COST CATEGORY	F.T.E.		AMOUNT
Administration	.50	Technical Assistant	$10,000.00
Secretarial and Support Staff	.25	Program Assistant	$ 6,853.00
Consultation	.05	Statistical	$ 1,991.00
	.05	Evaluation	$ 3,263.00
Computer/ Data Analysis			$ 1,200.00
		TOTAL	$23,307.00

FIGURE 4

HPIT PROJECT COSTS
UNIVERSITY OF WASHINGTON COSTS



Local Community Costs

Costs incurred by the local community (Whatcom and Thurston Counties) were considered under three categories. These costs were identified as;

1. local health department costs
2. participating hospital costs
3. participating physician's costs.

In both counties the direct implementation of the High Priority Infant Tracking Project is coordinated and carried out within the local community. In each county the local High Priority Infant Tracking Project Coordinator is an employee of the local health department. Infants who meet the criteria for inclusion in the tracking project are identified in local or participating hospitals by nurses or social services staff, physicians, or by local health department staff within the first thirty days of life. The majority of infants are identified in participating hospitals.

During the period examined, the participating hospitals and physicans donated their time to the High Priority Infant Tracking Project. The cost of their donated time has been estimated in order to provide information for counties and/or other agencies who may wish to implement a tracking system, as well as provide information as to the actual cost of the High Priority Infant Tracking Project. The projections

regarding the amount of time required to identify an high priority infant in the hospital setting, and the time required to complete the tracking phase was obtained directly from the IDENTIFICATION FORM,and the TRACKING FORM. Each form is designed to record the amount of time required. An average of all completed forms was used as a best estimate.

Health Department Costs

In both Whatcom and Thurston Counties, a community health nurse serves as the High Priority Infant Tracking Project Coordinator. As coordinator, this individual is primarily responsible for the successful implementation of the HPIT Project in the local community. Responsibilities include coordination and consultation with local physicians and hospital staff, and administration of the tracking phase of the project. The local health department is responsible for the timely mailing and receipt of TRACKING FORMS at the predetermined periods. In cases where an infant has not been seen by the primary care provider for routine well child care, the coordinator will attempt to reconnect them with the local health care system. The local coordinator also serves as a liason between the local hospitals and physicians, and the University of Washington and the State of Washington Maternal/Child Health Services staff.

For both counties, a projected amount of the miscellaneous costs incurred in the implementation of the project was included. These costs represent use of office machines, supplies, and materials, mileage, etc.

Whatcom County

Whatcom County began the High Priority Infant Tracking Project in October 1982. They have now completed 32 months of the tracking project. During the period from 7-1-84 to 6-30-85 344 forms were completed in Whatcom County. Of these 344 forms, 147 were new IDENTIFICATION FORMS. Approximately 270 infants who reside in Whatcom County participated in the High Priority Infant Tracking Project during the period examined. For each cost category the actual cost and the amount of time devoted to that category is computed for each operational month and annual cost. These costs are represented in TABLE 4.

At the present time the Whatcom County HPIT Project utilizes three major identification sites; St. Joseph Hospital, Bellingham WA, University Hospital and Children's Orthopedic Hospital and Medical Center, both in Seattle, WA.

TABLE 4

HPIT PROJECT COSTS
WHATCOM COUNTY HEALTH DEPARTMENT

COST CATEGORY	TIME (MO)	HOURLY WAGE	MONTHLY TOTAL	ANNUAL
Administration *(estimated)	18 min. (approx.)	$20.00	$ 5.94	$ 71.28
Secretarial/ Clerical	14 hr.	$ 9.60	$134.50	$1,614.00
Nursing/ Coordination	8 hr.	$18.66	$149.34	$1,792.08
Miscellaneous *(estimated)			$ 58.23	$ 698.76
Totals	22.3 hr.		$348.01	$4176.12

NOTE:
The estimated cost per child in Whatcom County for the period 7-1-84 to 6-30-85 based on 270 infants = $ 15.46 .

Thurston County

Thurston County began the High Priority Infant Tracking Project as a matched county in May, 1984. They have completed 13 months of the tracking project. During the time period examined, 244 forms were completed in Thurston County. Of these 244 forms, 129 were new IDENTIFICATION forms. Approximately 165 infants residing in Thurston County participated in the tracking project during this time period. Actual costs are represented in TABLE 5.

At the present time the Thurston County HPIT Project is served by five major identification sites;St.Peter Hospital, Olympia,WA, Tacoma General Hospital,Tacoma,WA,Madigan Army Medical Center,Tacoma,WA,University Hospital, Seattle,WA and Children's Orthopedic Hospital and Medical Center, Seattle,WA.

TABLE 5

HPIT PROJECT COSTS
THURSTON COUNTY HEALTH DEPARTMENT

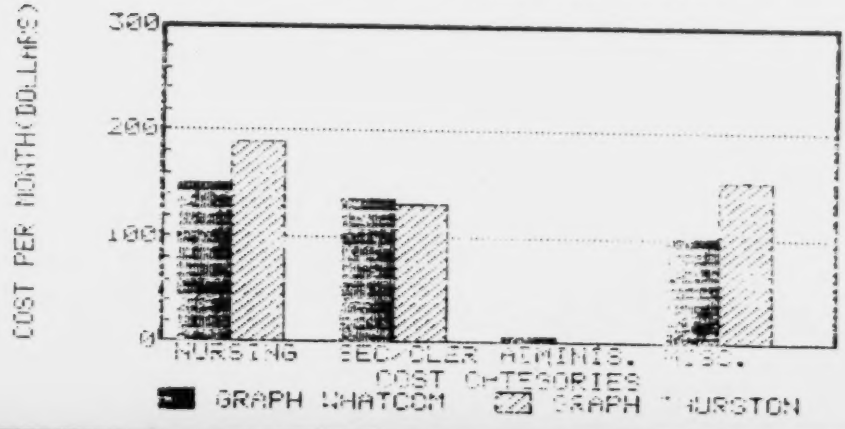
COST CATEGORY	TIME (MO)	HOURLY WAGE	MONTHLY TOTAL	ANNUAL
Administration	8 min.	$13.44	$ 1.80	$ 21.60
Secretarial	17.5 hr.	$6.60	$115.50	$1,386.00
Nursing/ Coordination	15.5 hr	$12.20	$189.10	$2,269.20
Clerical	2 hr.	$8.30	$ 16.60	$ 199.20
Miscellaneous (estimated)			$153.00 (approx.)	$1,836.00
Totals	35.13 hr		$476.00	$5,712.00

NOTE:
The estimated cost per child in Thurston County for the period 7-1-84 to 6-30-85 based on 165 infants = $34.61

The costs incurred in the Whatcom and Thurston County Health Departments is represented in Figure 5.

FIGURE 5

HPIT PROJECT COSTS
LOCAL HEALTH DEPARTMENT COSTS



Comparison of Whatcom and Thurston Counties

Cost variations between the two counties may be explained by several factors. The first and the most signinficant of these reasons is a difference in the actual implementation of the tracking project in each of the participating counties. Specific procedures which have been implemented within the Thurston County Health Department, such as the recording of public health department services used by each High Priority Infant prior to the mailing of the tracking form may partially account for the increase in hours devoted to the project. In addition, Thurston County is served by five identification sites, covering a wide geographical area. Whatcom County infants are identified at three sites. Written communication, inservice, and feedback to five identification sites may partially account increased costs in nursing and clerical services in the Thurston County Health Department. A third factor in the variation in costs may be partially accounted for by the fact that Whatcom County has participated for a longer period in the tracking project. Thurston County is in the "start up" phase of the the project. It is anticipated that as a local health department becomes more familiar with the identification and tracking process,the amount of time required, and the cost of the project will be reduced.

Participating Hospital Costs

In both Whatcom and Thurston Counties the participating hospitals are the primary source for the identification of infants who are eligible for the High Priority Infant Tracking Project. Based on a survey of the six participating hospitals, the following costs have been estimated as average costs incurred by the participating hospitals. The cost categories included nursing , administration, and chart review costs. Although each infant identified does not necessarily receive a chart review as a part of the identification process, it was frequently mentioned by nursing staff and administration during the survey. It is used primarily when infants are re-admitted to the hospital within the first thirty days of life, or are transferred to another facility, such as a tertiary care facility. The approximate cost of the chart review is included for information purposes. It should be noted that this chart review is separate from the chart review procedure used as an evaluation activity, which is discussed in the section entitled "Evaluation Costs".

For both counties the average amount of time related to the identification of High Priority Infants, and the cost of that time was computed by pooling the information gained from the six participating hospitals. The projected cost for the identification of one high priority infant in a hospital setting is represented in TABLE 6. This information is displayed in graph form in FIGURE 6.

TABLE 6

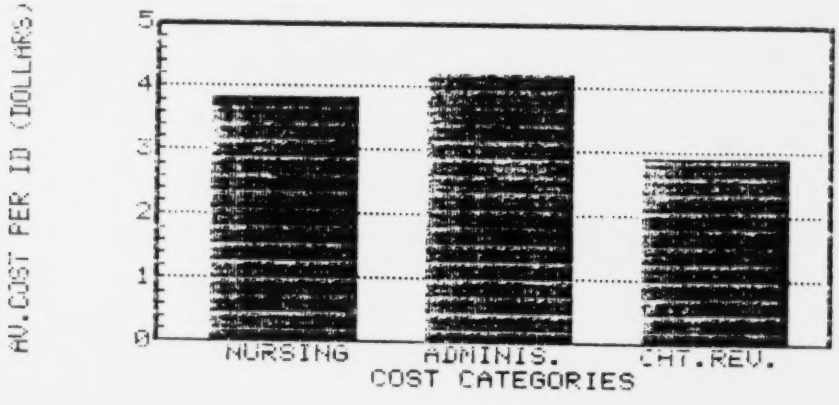
HPIT PROJECT COSTS
PROJECTED COST FOR THE IDENTIFICATION OF ONE INFANT
IN A HOSPITAL SETTING

Category	Average time	Average Hourly	Total
Administration	18 minutes	$14.00	$4.20
Nursing	20 minutes	$11.49	$3.83
Chart Review	10 minutes		$2.91
Totals	48 minutes		$10.94

NOTE:
The totals above are approximate costs and will vary from hospital to hospital and are also subject to variation between infants. They are provided only for informational purposes, and not as guidelines.

FIGURE 6

HPIT PROJECT COSTS
PROJECTED COST FOR THE IDENTIFICATION OF ONE INFANT
IN A HOSPITAL SETTING



Hidden Hospital Costs

A number of costs may be incurred by the participating hospitals which have not been reported here, and are difficult to accurately assess. These "hidden costs" which may occur can be characterized as;

1. costs incurred by staff discussion related to the identification of an infant, prior to the actual completion of the IDENTIFICATION FORM

2. costs incurred when staff go through the process of identification, and the process is terminated either by the decease of the patient, parent or primary care provider refusal of permission.

3. variations in the time, frequency and number of staff involved in inservice related to the High Priority Infant Tracking Project, both formally and informally.

These individual variations will account for variation in the cost of the project between hospitals, as well as the number of infants identified at each hospital.

Participating Physician Costs

As previously mentioned, during the time period examined the physicians and hospitals who participated in the High Priority Infant Tracking Project donated their time to the Project. The cost to the participating physician was examamined to determine the cost effectiveness of the total program. These costs were determined by survey of a random sample of the participating physicians.

In both Thurston and Whatcom Counties the primary care provider receives the TRACKING FORM at the predetermined tracking periods. In most cases it was reported that the primary care provider's clerical staff would pull the patient's chart, and after the physician had completed the TRACKING FORM , would return it by mail to the local health department. The amount of time involved and the approximate cost of that time is represented in TABLE 7. This data is also displayed in FIGURE 7.

TABLE 7

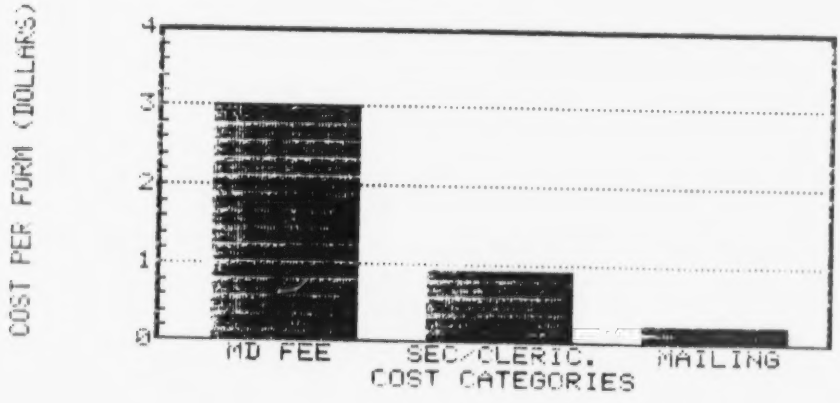
HPIT PROJECT COSTS
PROJECTED COST FOR THE COMPLETION OF ONE TRACKING FORM
IN A PARTICIPATING PHYSICIAN'S OFFICE

COST CATEGORY	TIME PER FORM	ESTIMATED HOURLY	COST PER FORM
Primary Care Provider	3 minutes	$60.00	$3.00
Secretarial/ Clerical	5 minutes	$11.16	$ .93
Mail			$ .22
Totals	8 minutes		$4.15

NOTE:
Variations in these approximate costs are to be expected within each particpating physician's office.
It was reported that in some instances the infants are so well known to the primary care provider that the TRACKING FORM can be completed without having to review the infant's chart, reducing the amount of time required, and therefore the cost of completing the form.

FIGURE 7

HPIT PROJECT COSTS
PROJECTED COST FOR THE COMPLETION OF ONE TRACKING FORM
IN A PARTICIPATING PHYSICIAN'S OFFICE



Evaluation Costs

Evaluation costs are incurred primarily at the University and are represented as personnel costs and data management and computer costs. In addition to these activities and costs, a hospital chart review is conducted biannually. This is conducted in order to determine the projected number of High Priority Infants who should be identified for each hospital and county. The labor cost of this activity is contained within the University personnel costs.

The cost of the chart review process was examined at each hospital by direct contact with the Director of Medical Records, and/or the hospital Budget Director. The average cost based on a review of the six hospitals was $1.00 per chart reviewed. This cost includes pulling the requested chart, and returning it to the files after the review has been completed. During an average project year the total number of charts reviewed for the six participating hospitals is projected at 725 charts. This projected cost is included in the summary of costs in TABLE 8 and FIGURE 8.

SUMMARY OF COSTS

Based on the information reported in this report of the real and projected costs involved with the High Priority Infant Tracking System it is possible to project the average cost per infant was for the time period examined. Approximately 435 infants were successfully tracked in Whatcom and Thurston Counties during the period from 07-01-84 to 06-30-85. The projected cost per infant was determined from the sum of the costs described in TABLE 8. FIGURE 8 displays this information in graph form.

TABLE 8

HPIT PROJECT COSTS
ANNUAL PROJECT SUMMARY COSTS

State MCH Costs	$14,626.50
University of Washington Costs	$23,307.00
Whatcom County Health Department Costs	$ 4,176.12
Thurston County Health Department Costs	$ 5,712.00
Hospital Costs; (276 IDENTIFICATION FORMS @ $10.94 each)	$ 3,019.44
Primary Care Provider Costs;(312 TRACKING FORMS @ $4.15 each)	$ 1,294.80
Chart Review *projected (725 charts)	$ 725.00
Total	$52,860.86
Project cost per infant based on 435 infants =	$ 121.52

BENEFITS OF THE HIGH PRIORITY INFANT TRACKING PROJECT

The cost of the High Priority Infant Tracking Project must be considered in relation to the benefits provided by such a system. The benefits of the tracking project can be summarized as:

1. A significant increase in the continuity of health care and developmental surveillance for High Priority infants. Prior to the implementation of HPIT over 50% of the High Priority infants in Whatcom and Thurston County were lost to follow-up before their third birthday. Since the implementation of the project the local health departments have successfully tracked and maintained in health care greater than 90% of the high priority infants enrolled in the system.

2. Public health nurse referrals in both counties have increased dramatically since the implementation of the project. One year after implementation of HPIT, Maternal Child Health referrals in Thurston County rose 27 percent over the previous two years. Two years after implementation, MCH referrals from St. Joseph Hospital to the Bellingham-Whatcom Health District rose 52 percent. In each district the public health nurses account for the increase as a direct result of the HPIT project.

3. The liason between community physicians, hospital personnel, and the public health departments has improved as a result of the HPIT project. In both counties, community health nurses and hospital nurses have reported improved cooperation and communication In both cases, personnel have been provided a forum for expressing concerns, and an opportunity to learn about the other's role.

4. Hospital nursery staff have benefited from ongoing inservice provided by their contacts with the local community health nurse on an informal basis, and on a more formal basis through inservice provided by university or MCH staff members. Hospital staff have become proficient in recognizing and referring infants who are at risk for developmental and/or medical problems. This increased sensitivity has led to increased referrals for other related services.

5. Returning high priority infants to the health care system improves the practice of community physicians by keeping high risk children in their care. By seeing children with complex health or developmental problems, physicians remain familiar with how to recognize, treat, and refer children with these problems. The quality of care for all children is improved through the promotion of preventive health care.

6. The liason between the state Maternal and Child Health Services, the University of Washington, the public health departments, and the participating hospitals has improved.

These reported benefits are the outcome of the improved intra-agency, and inter-agency communication that has been signficiantly influenced by the HPIT project. The greatest benefit of the tracking project is in the benefit to the high priority infant and his family. A philosophy of preventive health care and continuity with a local health care provider will enhance the quality of care for the high priority infant and may alter the families perspective regarding health care as a priority for other children.

SUMMARY

The High Priority Infant Tracking Project has successfully tracked over 400 infants to date. The oldest of these children is reaching the three year tracking stage. Multiple benefits have occured as a result of increased communication between local health care providers, hospital staff, and the local health departments. Increased sensitivity to the health care needs of a high priority population has resulted. The High Priority Infant Tracking Project has demonstrated that infants who are at risk for health and /or developmental problems can be successfully tracked and maintained in care with their local providers.

HIGH PRIORITY INFANT IDENTIFICATION FORM OF WASHINGTON STATE CASE NUMBER _____

PATIENT DATA

CHILD'S NAME _____ (last) (first) (middle)

DATE OF BIRTH _____ GESTATION (weeks) _____ ( ) Male ( ) Female

Infant born in this hospital. ( ) Yes ( ) No. If no, hospital of birth: _____

MOTHER'S NAME _____ (last) (first) (middle)

FATHER'S NAME _____ (last) (first) (middle)

GUARDIAN, if any _____ (last) (first) (relationship)

ADDRESS _____ (street or route no.) TELEPHONE _____

_____ (town)

_____ (county) (zip)

Name of persons other than parents who will know where child can be located:

1. _____ (name) (address) (telephone no.)

2. _____ (name) (address) (telephone no.)

HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)

( ) Birth weight ≤5 lbs. 8 oz. (≤2500 gms.) BIRTH WEIGHT _____ gms.

( ) Birth weight ≤10th %tile for gestational age (SGA) _____ lb. _____ oz.

( ) Head Circumference (OFC) ≤10th %tile or ≥90th %tile for gestational age OFC. _____ in./cms.

( ) Apgar score less than 4 at 5 minutes APGAR _____

( ) Intracranial hemorrhage

( ) Seizures

( ) Clinical impression of neurological abnormality DESCRIBE: _____

( ) Acquired CNS infection (e.g., meningitis) DESCRIBE: _____

( ) Hyperbilirubinemia (≥20 mg%) mg% _____

( ) Suspected/confirmed hearing impairment

( ) Suspected/confirmed visual impairment

( ) Major birth defect or syndrome DESCRIBE: _____

( ) Congenital fetal infection: ( ) toxoplasmosis ( ) rubella ( ) herpes ( ) cytomegalic virus ( ) syphilis

( ) Confirmed congenital hypothyroidism

( ) Confirmed PKU

( ) Mother 15 years of age or under AGE _____ yrs.

( ) Significant environmental, social, or parenting risk DESCRIBE: _____

( ) Other problems: _____

FORM COMPLETED BY: _____ DATE: _____

I have reviewed the above information and believe it to be correct.

_____ DATE: _____

(Attending Physician Signature)

PARENT'S PERMISSION

I have had the "High Priority Infant Tracking Program" explained to me orally and in writing and agree to having my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information as indicated above to my child's health care provider and to the local health department where my child resides presently or in the future. I understand I can withdraw my child from this program at any time. My child's health provider is:

_____ (name of health provider)

_____ (address) (town) (state) (zip)

_____ (Witness' Signature) (Parent's Signature)

_____ (Date) (Date)

( ) Refused tracking system: _____

TIME RECORD FOR THIS PATIENT

HOSPITAL STAFF

TIME SPENT ON HPIT: Please check appropriate time spent in each activity.

IDENTIFICATION (eg. identifying infant; preparing forms and charts, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.

( ) 30-35 min. ( ) Other specify in minutes: _____

PARENT CONTACT (eg. obtaining consent; explaining program, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.

( ) 30-35 min. ( ) Other specify in minutes: _____

HEALTH DISCIPLINE CONTACTS (eg. communication with other staff relative to HPIT activities)

( ) None ( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.

( ) 30-35 min. ( ) Other specify in minutes: _____

FORM SENT TO _____ CASE NUMBER _____

HIGH PRIORITY INFANT TRACKING FORM OF WASHINGTON STATE

PATIENT DATA

CHILD'S NAME _____ DATE OF BIRTH _____

PARENT'S NAME _____ TELEPHONE _____

ADDRESS _____

(street or route number) (town) (county) (zip)

If different from above, please correct: _____

RETURN FORM TO

AGENCY: _____ ATTENTION: _____ (person requesting information)

ADDRESS: _____ TELEPHONE: _____

Check TRACKING CONTACT ( ) 3-4 mos. ( ) 6-7 mos. ( ) 12 mos. ( ) 24 mos. ( ) 36 mos.

TRACKING DATA

Is this child still receiving health care from you? ( ) Yes ( ) No

If no, indicate reason: ( ) Don't know ( ) Cannot locate ( ) Deceased

( ) Moved to: _____ (state or county)

( ) Referred to another physician. _____

Address: _____

( ) Other: _____

Please indicate:

I HEALTH STATUS: ( ) Normal ( ) Other. If other, check **MAJOR** problems and specify as necessary below.

( ) A. CNS. ( ) Cerebral Palsy ( ) Seizures ( ) Hydrocephalus

( ) Structural defects, specify: _____

( ) Other: _____

( ) B. Pulmonary, specify: _____

( ) C. Cardiac, specify: _____

( ) D. Renal, specify: _____

( ) E. GI, specify: _____

( ) F. Growth Disorders: ( ) Failure to thrive

( ) Head Circumference (≤3rd %tile or ≥97th %tile)

( ) G. Malformation or syndromes, specify: _____

( ) H. Sociomedical: ( ) Child abuse/neglect ( ) Other, specify: _____

( ) I. Other, specify: _____

II BEHAVORIAL SENSORY DEVELOPMENT

A. Developmental Milestones — considering age (corrected for prematurity if any)

1. Personal-social:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
2. Fine motor:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
3. Gross motor:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
4. Language:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
5. Mental:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment

B. Vision: ( ) Normal ( ) Abnormal, specify: _____

C. Hearing: ( ) Normal ( ) Abnormal, specify: _____

D. Other, specify: _____

III. INTERVENTION SERVICES

A. With respect to the problems mentioned above, has the child and family received services from other community agencies during the past year?

( ) No ( ) Yes. If yes, specify type: _____

B. If no, why is the child not receiving these services? ( ) managing problems myself

( ) family refused ( ) appropriate services not available in community

TIME RECORD

FOR PRIMARY HEALTH CARE PROVIDER ONLY. Please check appropriate box indicating time spent in completing form.

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

CASE CLOSURE

FOR PHN ONLY:

Date of closure: _____ Reason: Moved out of ( ) state or ( ) county

( ) Parental permission withdrawn

( ) Cannot locate ( ) Deceased

TIME RECORD FOR THIS PATIENT

Time spent on HPIT. Please check appropriate time spent in activity

ADMINISTRATION (eg. developing file, sending tracking form, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

PARENT CONTACT (eg. activities related to tracking lost infant, follow-up, etc.)

( ) none ( ) 1-20 min. ( ) 31-60 min. ( ) 61-120 min. ( ) 2-3 hrs. ( ) 3-4 hrs.

( ) Other, please specify in hours _____

PRIMARY HEALTH CARE PROVIDER CONTACT (eg. communication relative to HPIT activities)

( ) none ( ) 1-10 min. ( ) 11-20 min. ( ) 21-31 min. ( ) 32-42 min. ( ) 43-53 min.

( ) 54-64 min. ( ) Other, please specify in hrs. _____

DSHS 13-588 (10/82) OS A-84

THE CONTINUITY OF CARE FOR HIGH PRIORITY INFANTS

THURSTON COUNTY PRE-PILOT STUDY REPORT

NOVEMBER 10,1985

UPDATED AUGUST -1986

Patricia J. Biro, Coordinator
High Priority Infant Tracking Project
CDMRC-446, WJ-10
University of Washington, Seattle, WA

The purpose of this study was to determine the degree of continuity of care for high priority infants within Thurston County prior to the implementation of the High Priority Infant Tracking Project. forty-eight infants with a mean age of thirty-one months were identified as having one or more high priority indicators through a chart review process. Fourteen physicians reporting on twenty-eight infants responded to a postal questionnaire. Current developmental and health status information was available for only eight infants. Seventeen infants in the study had either never made contact with the physician listed on the hospital discharge summary, or had dropped out of care before the time of the questionnaire. The mean age that these infants dropped out of health care was eight months. The reported results indicate that traditional methods of follow-up may not adequately meet the needs of a high priority population.

INTRODUCTION

In October 1982, the Washington State Parent and Child Health Services, in coordination with the University of Washington, implemented the High Priority Infant Tracking Project as a pilot project in Whatcom County, Washington. To further evaluate the effectiveness of this tracking system, Thurston County was added to the pilot project as a matched county in May 1984. The primary objectives of this project are as follows:

1. To assist the parents in securing or maintaining ongoing health supervision and developmental surveillance for their child through the first three years of life.

2. To facilitate the early identification of infants requiring further evaluation, intervention, and other support services.

3. To collect systematic data regarding state and local patterns of child health supervision, utilization of available resources, and incidence of disabilities among high priority infants, in order to improve health and educational services.

To date approximately 220 infants who reside in Thurston County are participating in cooperation with their primary care physicians in the tracking project.

PURPOSE

The purpose of this study was to determine the degree of continuity of care for high priority infants born in Thurston County prior to the implementation of the High Priority Infant Tracking Project. It was hoped that such a study would also help to evaluate the effectiveness of the tracking project as it is currently administered in Thurston County. Earlier studies have reported that as many as 50% of high priority infants may be lost to health care follow-up and developmental surveillance (McLaughlin, et al, 1984, and Padgett, 1984). Without ongoing health and developmental surveillance it is felt that many high priority infants may "slip through the cracks" and fail to obtain medical or educational interventions or services which may prevent or minimize potential health risks or disabilities.

METHOD

Five hospitals participated in the Thurston County Pri-Pilot Study; University Hospital, Seattle,WA Children's Orthopedic Hospital and Medical Center, Seattle, WA, St. Peter Hospital, Olympia,WA, Tacoma General Hospital, Tacoma, WA, and Madigan Army Medical Center, Tacoma, WA. These hospitals are currently participating the the High Priority Infant Tracking Project.

A chart review of infants born between October 1, 1982 and April 30, 1983 was conducted. A random sample of 10% of all births for this time period was conducted at the larger hospitals; St. Peter, and Madigan Army Medical Center. Due to the small number of births recorded in the other three hospitals, all charts were reviewed. Infants identified as "High Priority" had one or more of the eligibility criteria noted on the IDENTIFICATION FORM (see Appendix A). The chart review procedure was completed in April, 1985. Based on the results from the chart review forty-eight infants were targeted as the subject group. The number of high priority infants identified at each hospital is represented in Table I.

For each participating hospital a staff intermediary was selected to protect the confidentiality of the high priority infants and their families. For each identified infant, an introductory letter, a sample of the IDENTIFICATION FORM, and a Pre-Pilot Questionnaire (see Appendix B) was mailed to the primary care physician as listed on the hospital chart. Names of the identified infants were known only to the hospital intermediary and the primary care providers. The postal questionnaires were mailed in July and August, 1985.

RESULTS

Results were analyzed at the University of Washington in October, 1985. Of the forty-eight Pre-Pilot Questionnaires mailed, twenty-eight were returned (58% return rate). Of these, twenty-six were used for further data analysis. The primary care physician had been incorrectly recorded on the infant's hospital chart in the the remaining two cases and these questionnaires could not be used for further analysis.

Numbers of High Priority Infants per Hospital

TABLE I

Hospital	% of charts reviewed	Number Identified	Number Returned
COHMC	100	3	2
U of W	100*	0	0
St. Peter	10%	17	14
Tacoma General	100%	13	8
Madigan	10%	15	4
Totals		48	28

*During this time period, no infants from Thurston County were cared for at University Hospital.

Care after Discharge

In nine cases the primary care physican listed on the hospital chart had not cared for the infant after discharge. Six of these nine cases reported they did not know why they had not seen the infant. One case reported that the infant had moved, one infant was referred to another provider and in one case the infant was adopted. The name or address of the current primary care physician was not indicated, precluding any further follow-up. These nine cases were not used for any further analysis. In the remaining seventeen cases where care was provided to the infant after discharge additional health care information was obtained.

Table II represents the chronological ages of the infants at the time of the Pre-Pilot Study and the status of their health care. In addition, the age that the primary care physican reported they were last seen is listed.

TABLE II

Continuity of Care for 17 High Priority Infants

Case Number	Chronological Age	still under MD's care	Age Last Seen	Reason not Under Care
1.	34 months	no	12 months	unknown
2.	32 months	no	7 months	moved
3.	34 months	yes	n/a	n/a
4.	30 months	no	16 months	moved
5.	28 months	yes	n/a	n/a
6.	28 months	no	?blank	?blank
7.	29 months	no	3 months	unknown
8.	30 months	?(blank)	18 months	?blank
9.	30 months	yes	n/a	n/a
10.	30 months	yes	n/a	n/a
11.	33 months	yes	n/a	n/a
12.	31 months	yes	n/a	n/a
13.	31 months	no	12 months	referred
14.	31 months	no	12 months	referred
15.	31 months	no	2 months	unknown
16.	30 months	yes	n/a	n/a
17.	32 months	yes	n/a	n/a

X= 31 months* X= 8 months**

*Mean Chronological age at the time of the questionnaire

**Mean chronological age at the time of last visit to primary care physician.

Health Care In the First Year

Of the seventeen cases reporting, primary care physicians indicated that the infants in the study were seen for an average of four well child visits in the first year of life. The range of well child visits was from two to eight. Illness visits accounted for an average of three visits per child,with a range from zero to eleven. The average number of visits per child for immunizations was .33. Other visits in the first year were reported in four cases, with half of these being for acute illness.

Health Care in the Second Year

Health care in the the second year was reported for the nine cases that continued with their primary care physican. Only three children in this group received any well child visits in the second year (an average of .25 was obtained). Immunizations visits were reported for only one child. However, illness care was reported for nine cases, with an average of six illness visits per child in the second year. The range of illness visits was from one to nine. No information was available regarding other kinds of care provided during the second year.

Continuity of Care Post Discharge

For the twenty-six cases reporting, seventeen infants had received care from the primary care physician listed at the time of discharge (71%). Fifteen infants remained in care during all or part of the first year (63%). In the second year only nine infants still remained with the same primary care physican (38%). The average age at which the primary care physican reported last seeing the infant was eight months. These results are represented in TABLE III.

TABLE III

Continuity of Care for High Priority Infants

N=26

	% in care	% not in care
Post Discharge	65% (17/26)	35% (9/26)
During First Year	58% (15/26)	42% (11/26)
During Second Year	35% (9/26)	65% (17/26)

**The above percentages were obtained from primary care physician's reporting of the status of care in years one and two from the Pre-Pilot Questionnaire.

Ratings of Health and Development

Current health and developmental status was available for only nine infants who were still under care by their primary care physician. Of these nine infants, seven were reported as having normal development, one infant was reported as questionable, and one infant's status was reported as unkown. Ratings of health were reported as normal for five infants, abnormal in three infants, and unknown in one case. These findings are represented in Table IV and V.

TABLE IV

High Priority Infants Still Under Healthcare

N=9

Case Number	Chronological age	Health Status	Developmental Status
3.	34 months	normal	abnormal
5.	28 months	normal	normal
8.*	30 months	questionable	abnormal
9.	30 months	normal	normal
10.	30 months	unknown	unknown
11.	33 months	normal	normal
12.	31 months	normal	normal
16.	30 months	normal	normal
17.	31 months	abnormal	normal

* This infant was last seen at 18 months, but is presumed to still be under care.

TABLE V

Health and Developmental Status of High Priority Infants

N=8

	Normal Health	Questionable or Abnormal Health
Normal Development	5	2
Questionable or Abnormal Development	0	1

Use of Community Services

In the seventeen cases where care was provided after discharge only six infants (35%) reportedly used any community services. These were primarily referrals to other physicians or speciality clinics. Two cases had used local health department services, or supplemental food programs. Three infants used no community services. In the remaining eight cases, the primary care physician reported that it was unknown whether or not the infant and his or her family had used any community services.

DISCUSSION

The findings of the Thurston County Pre-Pilot Study indicate that traditional methods of health care follow-up and maintainence may not adequately meet the needs of a high priority infant population. Two significant findings in this study appear to be:

A. That high priority infants and their families are a highly mobile population. This is supported by the fact that only seven of the twenty-two respondants were still with the primary care physician noted at the time of discharge from the hospital.

B. That communication between hospital, physician, patient, and the family is imperfect. This finding is supported by the fact that seven infants failed to contact the physican listed as the primary care provider at the time of discharge from the hospital. In an additional eight cases the infants had dropped out of the physician's care without explaination prior to the time of the questionnaire. For these fifteen cases traditional methods of follow-up failed to provide adequate tracking of these children.

Together these findings indicate that it may be naive to presume that high priority infants are still under care when they fail to return to the primary care physician for service. It is our feeling that these infants do indeed "fall through the cracks" and do not obtain regular health and developmental surveillance. Despite the small number for whom current health and developmental status information was available (n=8) it is clearly evident that a significant

number of these infants experience later health and or developmental problems (38%). Clearly then, this is a population which warrants ongoing monitoring, and referral to services when appropriate.

Comparison to the Current Project

The High Prority Infant Tracking Project currently serves approximately 220 infants in Thurston County. The oldest of these infants are currently reaching the 18 month tracking period. The continuity of care for these infants is represented in Table VI.

TABLE VI

Continuity of Care for Infants in Thurston County as of March, 1986

	Infant Under Care	Infant Not Under Care
3 months	89% n=161	11% n=19
6 months	89% n=142	11% n=16
12 months	77% n=43	23% n=13

These figures indicate that an organized tracking system in coordination with the local health department and the high priority infant's primary health care provider can work together to insure that these infants recieve ongoing health and developmental surveillance. It is anticipated that as time progresses the tracking project will continue to document the success of this approach to the problem of ongoing health and developmental surveillance for high priority infants.

Limitations of the Study

The limitations of this study are recognized by the researchers and funding agencies involved. The small number of infants identified through the chart review process (n=38) limited the number of cases for analysis. The small sample size was further complicated by a incomplete return rate (74%) and limited reporting of some items.

In addition to these limitations the current study did not provide for a method of follow-up for those cases referred to another physician. In cases reportedly lost to follow-up with their recorded physician a parent contact may have determined if the child was still under care, and if so, who the current health care provider was. Due to confidentiality restrictions, parent contact was not possible.

Despite the limitations of the study, the results do offer information regarding the continuity of care for high priority infants in Thurston County. While we cannot state that infants who are no longer in care with their reported physicians are not receiving any health care services,their status is unknown to those care providers.

Further replication of this study would help to further illuminate the status of health care follow-up and developmental surveillance for high priority infants.

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WASHINGTON STATE

High Priority Infant Tracking Project

Evaluation Questionnaire Results

April, 1986

prepared by:

Patricia J. Biro, Coordinator
High Priority Infant Tracking Project
CDMRC-CTU
University of Washington
Seattle, WA 98195

*The Washington State High Priority Infant Tracking Project is a project of the Wasnington State Office of Parent-Child Health Services, Olympia, WA in coordination with the University of Washington, Seattle, WA.

Evaluation Questionnaire Report

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Section I

A. Introduction
B. Participants
C. Method

INTRODUCTION

In October, 1982 the Washington State Maternal and Child Health Services, in cooperation with the University of Washington, implemented the High Priority Infant Tracking Project (HPIT) as a pilot project in Whatcom County, Washington. To evaluate the effectiveness of the tracking system, Thurston County, Wasnington was added to the pilot project as a matched county in May, 1984. The primary objectives of the project are as follows:

1. To help parents keep their child under the care of their primary physician.

2. To promote early identification of infants requiring further evaluation, or services.

3. To assist in planning for the health and educational needs of the children of Washington State.

Enrollment into the HPIT project is initiated by identifying high priority infants according to "high priority" indicators listed on the IDENTIFICATION FORM (see Appendix A). Infants may be identified using one or more of the seventeen criteria including medical, social, parenting, or environmental risk factors. The IDENTIFICATION FORM is then completed, noting the risk factors identified, and consent is obtained from the infant's parents and the primary health care provider. A copy of this form is then sent to the public health department, and enrollment into the tracking system is completed.

A TRACKING FORM (see Appendix B) is sent to the infant's primary care provider at three months, six months, twelve months, eighteen months, twenty-four months, and thirty-six months. This form requests information regarding the infant's health and developmental status, use of community services and if the health care provider indicates the infant is not receiving care, the community health nurse attempts to locate the family and reconnect them with the health care system. Follow-up activities by the community health nurse may include written communication with the family and the primary care provider, telephone calls and home visits.

The High Priority Infant Tracking Project has now completed three full years of the pilot study. Ninety physicians have participated in the identification and tracking of high priority infants. Six hospitals; St. Joseph Hospital, Bellingham, WA, St. Peter Hospital, Olympia, WA, Madigan Army Medical Center, Tacoma, WA, Tacoma General Hospital, Tacoma, WA, Children's Orthopedic Hospital and Medical Center, Seattle, WA and University Hospital, Seattle, WA, have participated as identification sites. Over six hundred infants have been identified during the pilot phase in Whatcom and Thurston Counties. Greater than seventy-five percent of the eligible infants have been enrolled in the HPIT project and are currently being "tracked" through the project.

As a part of the program evaluation process for the High Priority Infant Tracking Project, an evaluation questionnaire was designed. The purpose of the questionnaire was to provide feedback from parents, health care providers, hospital and health department nursing and professional staff regarding their satisfaction with and perceptions of the project.

Participants

Participants were drawn from three groups: physicians, hospital and health department personnel, and parents.

Physicians from Whatcom and Thurston Counties who had participated in the HPIT Project were identified from the case log of HPIT Project enrollees. Ninety physicians were identified in this manner. The number of HPIT Project enrollees per doctor varied from one to fifty-eight. Nursing, clerical and administrative personnel who had been directly involved in the HPIT Project were identified from the Bellingham-Whatcom Health District and the Thurston County Health Department. For each of the six participating hospitals the HPIT Project liaison, administrators, and nursing personnel were identified. Twenty-six participants representing hopsital and health department personnel were identified to receive questionnaires.

To ensure the confidentiality of the respondents, parent participants were identified through HPIT Project case logs by the local health department HPIT coordinators. The names and addresses of the High Priority Infants and their families are not known by the Washington State Office of Parent Child Health Services or the University of Washington HPIT Project personnel. Four hundred thirty-one parents were identified as candidates to receive a questionnaire. Parents selected to receive a questionnaire had participated in the HPIT Project from one to thirty-six months.

No effort was made to randomize the selection of parents. All parents who were currently enrolled in the project were potential candidates for the postal questionnaire. A large return rate of undeliverable questionnaires was anticipated due to the potential high mobility of families with young infants. In order to assure an adequate representation of the parents who have participated, or are currently participating in the high priority infant tracking project all eligible parents were included in the sample.

Method

In February 1986, hospital and health department nursing and professional staff, and health care providers in Whatcom and Thurston County were sent a postal questionnaire. A stamped, self-addressed envelope was enclosed to encourage prompt return of the questionnaires.

In March 1986, the local health department High Priority Infant Tracking Project coordinators mailed questionnaires to the parents of project enrollees. Questionnaires were mailed from the local health department with a cover letter and a return envelope to the University of Washington. This was done to insure confidentiality of parent and infant names. Additionally, when questions arose, they could be directed to the local project coordinator.

Table 1 indicates the distribution of the questionnaires and the return rate by category

Table 1

HPIT Project: Evaluation Questionnaires

Category	N Mailed	N Returned	%
Primary Care Providers Whatcom/Thurston Counties	90	53	59%
*Nursing & Professional Staff	26	26	100%
Whatcom County Parents	217	79	36%
Thurston County Parents	214	73	34%

*This included staff from the Thurston County Health Department, Bellingham-Whatcom County Health District, St. Joseph Hospital, Bellingham, WA, St. Peter Hospital, Olympia, WA, Tacoma General Hospital, Tacoma, WA, Madigan Army Medical Center, Tacoma, WA, Children's Orthopedic Hospital and Medical Center, Seattle, WA, and University Hospital, Seattle, WA.

Return Rate

The greatest return rate was noted among the hospital/health department group (100%) where all questionnaires were returned. The physician return rate was 59 percent (N=53). In both Whatcom and Thurston Counties a small percentage of the questionnaires were returned as undeliverable. In Whatcom County this was 12 percent (27 questionnaires) and in Thurston County, 8 percent (18 questionnaires) were returned to the local health departments.

Section II

Analysis: Questions Related to Community Service and Project Objectives

A. Services to the Community
B. Assurance of Follow-Up
C. Estimation of the Occurrence of Disabilities
D. Identification of Health and/or Developmental Problems
E. Access to Community Services

Analysis

Analysis of the questionnaires was done categorically by the responding group, as well as by related questions. (See Appendix C for Sample Questionnaires.) The major topics addressed by the questionnaire were compared for measurement across groups.

All questions except one were based on a seven point Likert Scale indicating agreement or disagreement with each question. Scores between one and three were categorized as negative, or in disagreement with the questionnaire statement or question. A score of four (the midpoint) was categorized as neutral and scores of five and above are interpreted as agreeing with the statement, or a positive response.

Topic: In general the HPIT Project is a valuable community service.

Response:

Physicians

Physicians agreed with the value of the HPIT project by indicating a score of 5 or above sixty percent of the time (N = 29). Nineteen percent (N = 9) were neutral (score = 4) and twenty-one percent (N = 10) disagreed with the value of the project.

Hospital and Health Department

Hospital and health department staff indicated a forty-six percent agreement rate (N = 10), twenty-seven percent were neutral (N = 6), and twenty seven percent (N = 6) indicated disagreement by a score of three or below.

Parents

Parents indicated that they felt the project was a valuable community service. Seventy-six percent of the responses were scores of 5 or above (N = 103), sixteen percent (N = 22) were neutral, as indicated by a score of four. Eight percent (N = 17) did not agree, as indicated by a score of 3 or below.

A related question (see Parent Questionnaire Number 10) concerning the availability of a tracking program for all parents indicated similar results. Eighty-six percent (N = 113) of the responses were a five or above. Nine percent (N = 12) were neutral and five percent (N = 7) disagreed that the project should be available to all parents.

Discussion

Parent's strongly support the availability of a tracking project for all parents (86%) and the value of a tracking project in their community (75%). The majority of physicians (56%) felt the project was valuable. Health Department/Hospital staff were also supportive (46%) of the value of the project.

Topic: The HPIT Project is an efficient way of assuring follow-up of high priority infants.

Response:

Physicians

Forty-eight percent (N = 23) of the physicians rated this statement a five or above. Twenty-five percent (N = 12) were neutral. The remaining twenty-seven percent (N = 13) disagreed that the project is an efficient way to assure follow up.

Hospital and Health Department

Fifty-five percent (N = 12) rated the question a five or above. Five percent (N = 4) were neutral, and forty percent (N = 6) rated this item a three or below.

Parents

Thirty percent (N = 41) felt that the project helped to assure follow up. Twenty-four percent were neutral (N = 32) and the remaining forty-six percent (N = 68) did not agree as indicated by a score of 3 or less.

Discussion

The majority (55%) of hospital and health department respondents perceived the project as an efficient method of follow-up. The majority of physicians (48%) were also of the same opinion. The marked discrepancy between the perceptions of health care providers and parents, (only 23 percent rated a 5 or above) may be explained via the written comments by parents related to this question. Parents reported that the program did not make a significant difference in their follow up, and indeed many had forgotten they were enrolled in the project. Many parents indicated that their health care providers did not mention the project when tracking forms were completed. The design of the program is such that a parent would be contacted only if they had failed to return to their health care provider. This may have altered their perception of the efficiency of the project.

Topic: The HPIT Project helps estimate the occurence of disabilities in children.

Response:

Physicians

Sixty percent (N = 31) indicated agreement with the item by a score of five or above. Twenty-one percent (N = 11) were neutral. The remaining nineteen percent (N = 6) did not feel the project helped to estimate the occurence of disabilities.

Hospital and Health Department

Sixty-one percent (N = 14) indicated agreement with the item. Seventeen percent (N = 4) were neutral and twenty two percent (N = 5) disagreed.

Parents

Not applicable.

Discussion

Agreement was found between health care provider groups (physicians; 60%, Hospital/Health Department; 61%) regarding the ability of the project to estimate the occurence of disabilites. Both groups were in strong agreement (score of 5 or better) regarding this topic.

Topic: I use the HPIT Project to help identify infants with health and/or developmental problems.

Response:

Physicians

Only twenty-three percent (N = 11) of the responses indicated agreement with this topic. The majority of physicians (61%) strongly disagreed as indicated by a score of three or less; twenty-four percent (N = 1) were neutral.

Hospital and Health Department

Similar results were found in this group. Twenty-five percent (N = 5) agreed with the statement. Fifteen percent were neutral (N = 3) and the majority (60%) strongly disagreed (N = 12).

Parents

Not applicable.

Discussion

Similar results were obtained for both health care groups, the majority of physicians (61%), hospital and health department staff (60%) indicated that they do not use the HPIT Project to help identify infants with potential concerns. The responses may be indicative of the professional's desire to acknowledge their clinical skills, rather than project for their successful identification of health and developmental problems in high priority infants.

Topic: A) The HPIT Project has assisted me in providing appropriate evaluation, intervention, and/or support services as early as possible.

B) I believe the High Priority Infant Tracking Project helps to assure my child receives needed community services (e.g. public health nurse, referral to a specialist, infant stimulation programs, physical therapy, etc.)

Physicians

Parents

Response

A) Physicians responded to the statement regarding access to services by indicating disagreement in fifty percent of the responses (N = 23) twenty-eight percent were neutral (N = 13) and physicians demonstrated agreement in twenty-two percent of the cases (N = 10).

B) The majority of parents felt strongly that the HPIT project had improved access to community services. Fifty-five percent (N = 75) indicated agreement by a score of five or above. Thirteen percent (N = 18) were neutral and thirty-two percent (N = 44).

Discussion

The disparity between the parents' and physicians' perception of access to community services may be explained in part by the fact that the primary care provider may not be aware of all community services that a high priority infant and his family are using. In Whatcom County less than forty percent of the returned tracking forms from physicians indicate any use of community services. Even though these children may be using services, the physicians may not be aware of it. In Thurston County, known use of community services is recorded for each child prior to the completion of the tracking form by the primary care provider by the local health department staff. In Thurston County greater than forty percent of the high priority infants used one or more community services, and greater than sixty percent of those used the public health department services.

Section III

Analysis: Questions Related to Time Requirements

A. Identification and Tracking Forms
B. Follow-up for Children not Currently Under Care
C. Benefits vs. Time Requirements

Topic: Are the time requirements for the program reasonable and appropriate?

Responses to time requirements were evaluated individually for the completion of the Identification Form the Tracking Form by physicians and nurses, and also in three separate questions regarding the time required for health department personnel to coordinate the mailing process and follow-up on "lost" infants.

Responses: Identification Form

Physicians

Only fourteen percent (N = 6) indicated that the Identification Form required too much time to complete. The majority of physicians, sixty-six percent (N = 30) indicated that the time required was not a problem. Twenty percent were neutral.

Hospital and Health Department

Sixteen percent (N = 4) agreed that the form required too much time. The majority, forty six percent (N = 11) felt the time requirement was appropriate. Thirty-eight percent (N = 9) were neutral.

Tracking Form:

Response:

Physicians

Physicians are primarily responsible for completing the Tracking Forms and returning them to the local HPIT Project coordinator. The majority, sixty-three percent (N = 29) indicated the time requirements were appropriate. Twenty-four percent (N = 11) were neutral and thirteen percent (N = 6) indicated the form took too much time.

Health Department Staff

The local public health departments are responsible for the mailing and management of the tracking forms. Of the seven polled, fifty-seven percent (N = 4) did not feel the time required to mail the forms was excessive. Twenty-nine percent (N = 2) were neutral and fourteen percent (N = 1) felt the time required was too great.

Follow-up

The health department staff were polled regarding the time required to follow up on high priority infants who were reportedly no longer in care with their original primary care provider. Of the seven respondents, forty three percent (N = 3) felt the time requirement was not excessive and the majority, fifty-seven percent (N = 4) felt the time was too great.

Benefits vs. Time

Seventy-one percent of the seven health department respondents (N = 5) indicated strongly, that the benefits of the HPIT Project offset the time requirements. Twenty-nine percent (N = 2) were neutral.

Discussion

The time requirements for completion of the Identification and Tracking Forms does not appear to be excessive. Several physicians and hospital staff indicated in the comments section that while individually the forms did not require excessive time, the cumulative effect of the frequent tracking periods, and multiple clients does become burdensome.

The time requirements are greatest for the local health department personnel who coordinate the HPIT project at the local level and provide follow-up for lost cases. They indicated that the time required was not excessive, and that the benefits outweighed the time requirements.

Further evaluation of the time requirements is indicated.

Section IV

Analysis: Questions related to the role of the state in Tracking High Priority Infants.

A) Financial Involvement
B) Level of Involvement

Topic: The HPIT project can only be continued with state financial support.

Response:

Physicians:

The majority of physicians, forty-two percent (N=17) strongly agreed that state financial support is necessary. Thirty-eight percent (N=16) were neutral, and twenty percent (N=8) disagreed.

Hospital/Health Department:

The majority of the health department/hospital respondents, eighty-two percent (N=14) felt state financial support was needed. Six percent (N=1) were neutral and twelve percent (N=2) disagreed.

Parents:

Parents were asked to respond to a similar question (see Parent Questionnaire #7) regarding state involvement in a tracking project for high priority infants. The majority of parents seventy-nine percent (N=110) responded that they agreed with state involvement. Fourteen percent (N=20) were neutral and eleven percent (N=9) disagreed with state involvement.

Discussion:

Healthcare providers were in agreement regarding state financial support for the HPIT Project. Parents also strongly supported state involvement in a tracking project.

Topic: Tracking is adequate without state involvement.

Physicians and hospital/health department personnel were asked to respond to questions regarding the adequacy of tracking with an organized system. (See Physician Questionnaire #11, and Public Health/Hospital Questionnaire #8.) In addition both groups were asked to indicate if infants enrolled in the project received improved followed up. (See Physician Questionnaire #13 and Public Health/Hospital Questionnaire #12.)

Response:

Physicians:

The majority of physicians sixty-two percent (N=26) indicated that tracking was not adequate without a state program. Twenty-one percent (N=9) were neutral and seventeen percent (N=7) agreed that tracking of high priority infants was adequate without a state program.

Physicians indicated that infants enrolled in the project received the same care as before the project in fifty-eight percent (N=21) of the responses. Thirty-nine percent (N=14) felt the follow-up care was better, and three percent (N=1) indicated that follow-up was worse than before.

Hospital/Health Department

The majority of the respondents; sixty-two percent (N=13) indicated that state involvement was needed for an adequate tracking project. Ten percent (N=2) were neutral and twenty-eight percent (N=6) indicated that tracking was adequate without state involvement. When asked to rate the follow-up care for infants enrolled in the HPIT project compared to those infants born before the initiation of the project, the majority of respondents fifty-nine percent (N=13) indicated follow-up was the same. Forty-one percent (N=9) felt that follow-up had improved, as a result of the project.

Discussion:

Strong support for state involvement in an organized tracking system was indicated by both healthcare providers (62%) and professional staff in the hospitals and health departments (62%). As discussed early, the majority of parents (79%) also strongly supported state involvement in tracking high priority infants.

Both healthcare groups tended to feel follow-up care was the same as before the tracking system was implemented.

Section V

Analysis: Questions related to specific program activities

A. Tracking Schedule
B. Parent Brochure
C. Staff Explanation of the Project

Topic: The present tracking schedule of three, six, twelve, eighteen, twenty-four and thirty-six months is appropriate.

Response:

Physicians:

The majority; sixty-one percent (N=27) agreed that the present schedule was appropriate. Twenty one percent (N=9) were neutral and eighteen percent (N=8) disagreed with the present tracking schedule.

Hospital/Health Department:

The majority agreed with the present schedule; seventy-two percent (N=16) of the respondents indicated a score of five or above. Fourteen percent were neutral (N=3) and fourteen percent (N=3) disagreed with the present schedule.

Discussion:

Health care professions were largely supportive of the present schedule of tracking periods. Comments related to this topic were recorded. Several suggestions were made to reduce the number of tracking periods, or eliminate specific periods, to reduce the amount of paper work.

Topic:

A) Does the HPIT Brochure adequately explain the project.

B) Do hospital staff explain the HPIT project to parents adequately.

Response:

Hospital/Health Department:

Respondents indicated that the brochure does an adequate job of explaining the project. Sixty-eight percent (N=13) indicated a score of five or above. Twenty-one percent (N=4) were neutral and eleven percent (N=2) did not feel the brochure was adequate.

Parents:

The majority of parents; sixty-two percent (N=80) felt the brochure explained the project well. Fourteen percent (N=17) were neutral and twenty-four percent (N=19) did not feel the brochure was adequate.

The parents perceptions regarding the ability of the hospital staff to explain the project indicated that the majority of parents; sixty-three percent (N=84) felt that the staff did a good job. Eight percent (N=16) were neutral and twenty-nine percent (N=38) did not feel the staff explained the project well.

Discussion:

Many parent comments were noted regarding the brochure. One parent was unable to read English, and a translator was not available to interpret the brochure. Frequently parents indicated they had never received a brochure.

In general, the HPIT Project brochure appears to be explaining the project well to parents. Suggestions for modifications included the addition of schedules for immunizations and well-child visits.

Section VI

Analysis: Questions Related to Privacy, Worry, and the Appropriate Identification of High Priority Infants

A. Appropriate Identification
B. Invasion of Privacy
C. Worry or Concern Due to Enrollment

Topic:

Several questions were related to the parents perception of the appropriateness of the the identification of their infant, their invasion of privacy (see Parent Questionnaire, numbers 8 and 9) as well as the physician's perception of the worry or concern caused parents by the identification, and enrollment of their child in the HPIT project. (See Physician Questionnaire, #10.)

Response:

Parents

A. The majority of parents, sixty-seven percent (N=91) agreed that their infant had been appropriately identified. Fourteen percent (N=18) were neutral and nineteen percent (N=26) feels their infants were not appropriately identified as "high priority."

B. Parents indicated that enrollment had not invaded their privacy in an overwhelming majority, ninety-one percent (N=126). Three percent (N=5) were neutral and six percent (N=8) indicated that their privacy had been invaded by enrollment in the project.

Physicians:

C. The majority of physicians, sixty percent (N=25) agreed with the views of the parents that enrollment inthe HPIT project had not caused unnecessary worry. Twenty-six percent (N=11) were neutral and fourteen percent (N=6) indicated that they felt the project had caused parents to worry.

Discussion:

Both parents and physicians appear to be in agreement that the HPIT project does not cause parents needless worry or concern.

Further, it appears that parents do not perceive the identification of their infant as high priority, and his or her subsequent enrollment in the project as an invasion of privacy.

Section VII

Analysis: Questions Related to the Quality of Care for High Priority Infants

Topic: Does enrollment in the HPIT project improve the delivery of health care for high priority infants and their families?

Parents were asked to respond to two questions regarding the quality of health care related to the HPIT project. (See Parent Questionnaire #s 11 and 12.)

Response:

The majority of parents did not feel the health care of their family had improved as a result of enrollment in the HPIT Project. Fifty-six percent (N=79) strongly disagreed that their care was improved. Twenty percent (N=24) were neutral and twenty-four percent (N=32) felt that the HPIT project and improved the health care of their family.

Similar response were obtained regarding the quality of health care for their infants. The majority of parents; fifty-five percent (N=75) felt there was not a difference in care for their infant. Twenty-two percent (N=30) were neutral. Twenty-three percent (N=31) felt that enrollment had improved the care for their infant.

Discussion:

Many parent comments regarding this topic were noted. These comments appear in Appendix D; Comments. Parent's indicated via their written comments that they would expect the best possible healthcare from their providers regardless of enrollment in the HPIT Project. Many positive comments regarding the quality of care were recorded.

Section VIII

Analysis: Questions Regarding Continued Participation in the HPIT Project

Topic: Continued participation in the HPIT Project.

Response

Health care professionals were polled regarding their desire to continue participation in the HPIT project. Physicians indicated that the majority; fifty-eight percent (N=26) were in favor of continued participation. Eighteen percent were neutral and twenty-four percent (N=12) indicated that did not support continued participation.

Hospital and Health department personnel also indicated support for their continued participation in the HPIT project. Forty-eight percent (N=10) were supportive of continued participation, twenty-eight percent (N=6) were neutral and twenty-four percent (N=5) did not support continued involvement.

Discussion

Continued support for the HPIT project is indicated. It should be noted that during the pilot study hospital personnel and primary healthcare providers received no direct financial reimbursement for participation in the HPIT Project.

Section IX

Summary

The results of the HPIT Project Evaluation Questionnaire indicate support for the project from physicians, nurses, professional staff and parents. The project is perceived as an efficient system for the estimation of disabilities in infants and young children, and assurance of medical follow up.

Broad support for the involvement of the state in a tracking project was noted for all groups polled. Tne respondents supported state financial support and parents additionally supported the availability of the project for all parents of a high priority infant.

Enrollment in the HPIT Project did not appear to be an invasion of privacy for parents, or cause them undue worry. The majority of parents felt that their infant was appropriately identified as "high priority." Parents also reported that the HPIT Project Brochure and the hospital staff did an adequate job of explaining the project, when provided.

Specific recommendations for the modification of the time requirements, protocol, tracking periods, and parent brochure were obtained from physicians, nurses, and other professional staff. While the time requirements for the project are significant, the benefits appear to outweigh the time requirements.

Appendices

Appendix A: Identification Form

Appendix B: Tracking Form

Appendix C: Sample Questionnaires

Appendix D: Comments

APPENDIX A

HIGH PRIORITY INFANT IDENTIFICATION FORM OF WASHINGTON STATE CASE NUMBER _____

PATIENT DATA

CHILD'S NAME: _____ (last) _____ (first) _____ (middle)

DATE OF BIRTH: _____ GESTATION (weeks): _____ ( ) Male ( ) Female

Infant born in this hospital: ( ) Yes ( ) No. If no, hospital of birth: _____

MOTHER'S NAME: _____ (last) _____ (first) _____ (middle)

FATHER'S NAME: _____ (last) _____ (first) _____ (middle)

GUARDIAN, if any: _____ (last) _____ (first) _____ (middle) _____ (relationship)

ADDRESS: _____ (street or route no.) _____ (town) TELEPHONE _____

_____ (county) _____ (zip)

Name of persons other than parents who will know where child can be located:

1. _____ (name) _____ (address) _____ (telephone no.)

2. _____ (name) _____ (address) _____ (telephone no.)

HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)

( ) Birth weight ≤5 lbs. 8 oz. (≤2500 gms.) BIRTH WEIGHT _____ gms.

( ) Birth weight ≤10th %tile for gestational age (SGA) ____ lb. ____ oz.

( ) Head Circumference (OFC) ≤10th %tile or ≥90th %tile for gestational age OFC. ____ in./cms.

( ) Apgar score less than 4 at 5 minutes APGAR _____

( ) Intracranial hemorrhage

( ) Seizures

( ) Clinical impression of neurological abnormality DESCRIBE: _____

( ) Acquired CNS infection (e.g., meningitis) DESCRIBE: _____

( ) Hyperbilirubinemia (≥20 mg%) mg% _____

( ) Suspected/confirmed hearing impairment

( ) Suspected/confirmed visual impairment

( ) Major birth defect or syndrome DESCRIBE: _____

( ) Congenital fetal infection: ( ) toxoplasmosis ( ) rubella ( ) herpes ( ) cytomegalic virus ( ) syphilis

( ) Confirmed congenital hypothyroidism

( ) Confirmed PKU

( ) Mother 15 years of age or under

( ) Significant environmental, social, or parenting risk DESCRIBE: _____ AGE ____ yrs.

( ) Other problems: _____

FORM COMPLETED BY: _____

I have reviewed the above information and believe it to be correct. DATE: _____

(Attending Physician Signature) DATE: _____

PARENT'S PERMISSION

I have had the "High Priority Infant Tracking Program" explained to me orally and in writing and agree to having my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information as indicated above to my child's health care provider and to the local health department where my child resides presently or in the future. I understand I can withdraw my child from this program at any time. My child's health provider is:

_____ (name of health provider)

_____ (address) (town) (state) (zip)

_____ (Witness Signature) (Parent's Signature)

_____ (Date) (Date)

( ) Refused tracking system: _____

TIME RECORD FOR THIS PATIENT

HOSPITAL STAFF

TIME SPENT ON HPIT: Please check appropriate time spent in each activity.

IDENTIFICATION (eg. identifying infant; preparing forms and charts, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.

( ) 30-35 min. ( ) Other specify in minutes: _____

PARENT CONTACT (eg. obtaining consent, explaining program, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.

( ) 30-35 min. ( ) Other specify in minutes: _____

HEALTH DISCIPLINE CONTACTS (eg. communication with other staff relative to HPIT activities)

( ) None ( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.

( ) 30-35 min. ( ) Other specify in minutes: _____

APPENDIX B

FORM SENT TO: _____ CASE NUMBER _____

HIGH PRIORITY INFANT TRACKING FORM OF WASHINGTON STATE

PATIENT DATA

CHILD'S NAME: _____ DATE OF BIRTH: _____

PARENT'S NAME: _____ TELEPHONE: _____

ADDRESS: _____

(street or route number) (town) (county) (zip)

If different from above, please correct: _____

RETURN FORM TO

AGENCY: _____ ATTENTION: _____

(person requesting information)

ADDRESS: _____ TELEPHONE: _____

Check TRACKING CONTACT:( ) 3-4 mos.( ) 6-7 mos.( ) 12 mos.( ) 18 mos.( ) 24 mos.( ) 30 mos.( ) 36 mos.

TRACKING DATA

Is this child still receiving health care from you? ( ) Yes ( ) No

If no, indicate reason: ( ) Don't know ( ) Cannot locate ( ) Deceased

( ) Moved to: _____ (state or county)

( ) Referred to another physician: _____

Address: _____

( ) Other: _____

Please indicate:

I. HEALTH STATUS: ( ) Normal ( ) Other. If other, check MAJOR problems and specify as necessary below.

( ) A. CNS. ( ) Cerebral Palsy ( ) Seizures ( ) Hydrocephalus

( ) Structural defects, specify: _____

( ) Other: _____

( ) B. Pulmonary, specify: _____

( ) C. Cardiac, specify: _____

( ) D. Renal, specify: _____

( ) E. GI, specify: _____

( ) F. Growth Disorders: ( ) Failure to thrive

( ) Head Circumference (≤3rd %tile or ≥97th %tile)

( ) G. Malformation or syndromes, specify: _____

( ) H. Sociomedical: ( ) Child abuse/neglect ( ) Other, specify: _____

( ) I. Other, specify: _____

II. BEHAVORIAL/SENSORY DEVELOPMENT

A. Developmental Milestones — considering age (corrected for prematurity if any)

1. Personal-social: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
2. Fine motor: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
3. Gross motor: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
4. Language: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment
5. Mental: ( ) Normal ( ) Questionable ( ) Abnormal ( ) in treatment

B. Vision: ( ) Normal ( ) Abnormal, specify: _____

C. Hearing: ( ) Normal ( ) Abnormal, specify: _____

D. Other, specify: _____

III. INTERVENTION SERVICES

A. With respect to the problems mentioned above, has the child and family received services from other community agencies during the past year?

( ) No ( ) Yes. If yes, specify type: _____

B. If no, why is the child not receiving these services? ( ) managing problems myself

( ) family refused ( ) appropriate services not available in community

Date last seen by you _____

TIME RECORD

FOR PRIMARY HEALTH CARE PROVIDER ONLY: Please check appropriate box indicating time spent in completing form.

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

CASE CLOSURE

FOR PHN ONLY:

Date of closure: _____ Reason: Moved out of ( ) state or ( ) county

( ) Parental permission withdrawn

( ) Cannot locate ( ) Deceased

TIME RECORD FOR THIS PATIENT

Time spent on HPIT: Please check appropriate time spent in activity

ADMINISTRATION (eg. developing file; sending tracking form, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

PARENT CONTACT (eg. activities related to tracking lost infant; follow-up, etc.)

( ) none ( ) 1-20 min. ( ) 31-60 min. ( ) 61-120 min. ( ) 2-3 hrs. ( ) 3-4 hrs.

( ) Other, please specify in hours _____

PRIMARY HEALTH CARE PROVIDER CONTACT (eg. communication relative to HPIT activities)

( ) none ( ) 1-10 min. ( ) 11-20 min. ( ) 21-31 min. ( ) 32-42 min. ( ) 43-53 min.

( ) 54-64 min. ( ) Other, please specify in hrs. _____

COPY TO: WHITE — HEALTH DEPARTMENT CANARY — HPIT PROJECT

DSHS 13 660 (3/85) OS A 96

APPENDIX C

SAMPLE QUESTIONNAIRE #1

HIGH PRIORITY INFANT TRACKING PROJECT

(HPIT)

PHYSICIAN EVALUATION QUESTIONNAIRE

PLEASE COMPLETE THE FOLLOWING QUESTIONNAIRE BY CIRCLING THE NUMBER WHICH BEST CORRESPONDS TO YOUR OPINION OF THE HIGH PRIORITY INFANT TRACKING PROJECT (HPIT).

	STRONGLY DISAGREE						STRONGLY AGREE
1. In general the HPIT Project is a valuable community service.	1	2	3	4	5	6	7
2. The HPIT Project is an efficient way of assuring follow-up of high priority infants.	1	2	3	4	5	6	7
3. The HPIT Project helps estimate the occurence of disabilities in children.	1	2	3	4	5	6	7
4. I use the HPIT Project to help identify infants with health and/or developmental problems.	1	2	3	4	5	6	7
5. The HPIT Project has assisted me in providing appropriate evaluation, intervention, and/or support services as early as possible.	1	2	3	4	5	6	7
6. The Identification Form takes too much time to complete.	1	2	3	4	5	6	7
7. The Tracking Form takes too much time to complete.	1	2	3	4	5	6	7
8. This project can only be continued with state financial support.	1	2	3	4	5	6	7

	STRONGLY DISAGREE						STRONGLY AGREE
9. The present tracking schedule of three, six, twelve, eighteen, 24 and 36 months is appropriate.	1	2	3	4	5	6	7
10. The identification of high priority infants has NOT caused parents unnecessary worry.	1	2	3	4	5	6	7
11. High Priority Infant Tracking is adequate WITHOUT a state-wide organized program.	1	2	3	4	5	6	7
12. I would like to continue participation in the HPIT Project.	1	2	3	4	5	6	7

13. Infants enrolled in the HPIT Project receive the (_____) same, (_____) better, or (_____) worse, follow-up as did high priority infants identified before the HPIT Project was implemented.

14. I would like to see the following changes in the HIGH PRIORITY INFANT TRACKING PROJECT:

THANK YOU FOR YOUR CONTINUED INTEREST AND ASSISTANCE WITH THE HIGH PRIORITY INFANT TRACKING PROJECT. PLEASE RETURN YOUR QUESTIONNAIRE IN THE ENCLOSED ENVELOPE.

revised 1/86

SAMPLE QUESTIONNAIRE #2

HIGH PRIORITY INFANT TRACKING PROJECT

(HPIT)

HOSPITAL/HEALTH DEPARTURES EVALUATION QUESTIONNAIRE

PLEASE COMPLETE THE FOLLOWING QUESTIONNAIRE BY CIRCLING THE NUMBER WHICH BEST CORRESPONDS TO YOUR OPINION OF THE HIGH PRIORITY INFANT TRACKING PROJECT (HPIT).

	STRONGLY DISAGREE						STRONGLY AGREE
1. In general, the HPIT Project is a valuable community service.	1	2	3	4	5	6	7
2. The HPIT Project is an efficient way of assuring follow-up of high priority infants.	1	2	3	4	5	6	7
3. The HPIT Project helps estimate the occurrence of disabilities in children.	1	2	3	4	5	6	7
4. I use the HPIT Project to help identify infants with health and/or developmental problems.	1	2	3	4	5	6	7
5. The HPIT Project brochure adequately explains the HPIT Project to parents.	1	2	3	4	5	6	7
6. The Identification Form takes too much time to complete.	1	2	3	4	5	6	7
7. This project can only be continued with state financial support.	1	2	3	4	5	6	7
8. Tracking of High Priority Infants is adequate WITHOUT a state-wide organized program.	1	2	3	4	5	6	7

	STRONGLY DISAGREE						STRONGLY AGREE
9. Participation in the HPIT Project has improved my ability to recognize biological and environmental risk factors.	1	2	3	4	5	6	7
10. The present tracking schedule of three, six, twelve, eighteen, 24 and 36 months is appropriate.	1	2	3	4	5	6	7
11. I would like to continue participation in the HPIT Project.	1	2	3	4	5	6	7

12. Infants enrolled in the HPIT Project receive the (_____) same, (_____) better, or (_____) worse follow-up as did high priority infants identified before the poject was implemented.

HEALTH DEPARTMENT PERSONNEL: Please answer Question #13, #14, and #15. Otherwise go to Question #16.

13. It takes too much time to send out tracking forms to the appropriate physicians.	1	2	3	4	5	6	7
14. It takes too much time to follow up on High Priority infants once lost by their private physician.	1	2	3	4	5	6	7
15. The benefits of the HPIT Project are worth the time required.	1	2	3	4	5	6	7

16. I would like to see the following changes in the HIGH PRIORITY INFANT TRACKING PROJECT:

THANK YOU FOR YOUR CONTINUED INTEREST AND ASSISTANCE WITH THE HIGH PRIORITY INFANT TRACKING PROJECT. Please return your questionnaire in the enclosed envelope.

SAMPLE QUESTIONNAIRE #3

HIGH PRIORITY INFANT TRACKING PROJECT

(HPIT)

PARENT EVALUATION QUESTIONNAIRE

PLEASE COMPLETE THE FOLLOWING QUESTIONNAIRE BY CIRCLING THE NUMBER WHICH BEST INDICATES YOUR OPINION OF THE HIGH PRIORITY INFANT TRACKING PROJECT (HPIT).

	STRONGLY DISAGREE						STRONGLY AGREE
1. I believe the High Priority Infant Tracking Project helped maintain regular check-ups and care for my child with his/her physician.	1	2	3	4	5	6	7
2. I believe the High Priority Infant Tracking Project helps to assure my child receives needed community services (e.g., public health nurse, referral to a specialist, infant stimulation programs, physical therapy, etc.).	1	2	3	4	5	6	7
3. I feel the High Priority Infant Tracking Project is a valuable service to my community.	1	2	3	4	5	6	7
4. The High Priority Infant Tracking Project Parent Brochure explained the project well.	1	2	3	4	5	6	7
5. The hospital staff explained the High Priority Infant Tracking Project to me in a way I could understand.	1	2	3	4	5	6	7
6. I became unnecessarily worried about my child's health due to being enrolled in the High Priority Infant Tracking Project.	1	2	3	4	5	6	7

	STRONGLY DISAGREE						STRONGLY AGREE
7. I believe state involvement in organizing a tracking program for high priority infants is beneficial.	1	2	3	4	5	6	7
8. I feel my privacy has been invaded by having my infant enrolled in the High Priority Infant Tracking Project.	1	2	3	4	5	6	7
9. I felt my infant was appropriately identified as "high priority."	1	2	3	4	5	6	7
10. I feel that participation in the High Prioroity Infant Tracking Project is a service that should be available for all high priority infants and their families.	1	2	3	4	5	6	7
11. I feel that the health care of my family has improved as a result of the High Priority Infant Tracking Project.	1	2	3	4	5	6	7
12. I feel that my physician provides my infant with better care as a result of our participation in the High Priority Infant Tracking Project.	1	2	3	4	5	6	7

COMMENTS:

THANK YOU FOR YOUR ASSISTANCE IN EVALUATING THE HIGH PRIORITY INFANT TRACKING PROJECT. Please return your completed questionnaire in the enclosed envelope.

APPENDIX D

HIGH PRIORITY INFANT TRACKING PROJECT: PARENT COMMENTS

I was very concerned about my twins as they had specific problems at birth. I have felt much more secure being involved in this program. I have a strong feeling of having helped avoid many problems with this program. Please continue it for other parents peace of mind. Thank you.

I do not feel that HPIT program offers much to my family. I am a registered nurse and am highly motivated to follow closely my child's development and special needs. I do feel the program would be very valuable to people with less awareness and motivation for regular medical care than we are.

It was hard for me to evaluate the system since my child did not require any special services after her stay in the hospital. Also the childrens pediatrician was already providing the best care and interest before my baby was born. So it is hard to say whether or not the care of the baby is better or if the care of the other children has improved.

We have not heard of the HPIT since the day we left the hospital. Our phsician has never brought it up in any of her check-ups.

Althougn I don't believe my daughter had major medical problems the HPIT Project was very beneficial to me as a form of reassurance and answering my questions. Our family was having a tough time and it was wonderful to have the public health nurse there to help me and offer support. I believe in the HPIT Project.

I feel this is a good program but we would have regular medical checkups for our baby regardless of this program. The hospital staff forgot to explain this program before our child was discharged.

I think it is a very good program. However I didn't feel my son really fitted the bill as far as being a "High Priority Infant." His birth weight ws 9 lb. 6 oz. and I was 30 at his birtn. That really isn't that big of a deal. But I really appreciate your concern and just knowing tnat extra help was available gave peace of mind. Thanks!

This would be a valuable service to the needy. Apparently my child was not high priority enough to need follow-up care.

My child has a birth defect that has been corrected. I really appreciated your services.

Our correctable defect required two operations at age one but really nothing extra could be done while waiting--and nothing done since the (successful) operation--these facts influenced my answers.

I think this is a wonderful program and hope it continues for years to come.

Our daughter was very healthy by the time she was 12 days old. Other than being "Premature" she really wasn't in need of the services offered through the program. Because of her good health we weren't involved in the program enough to give a qualified opinion or evaluation. I was very concerned about our privacy, but we weren't bothered personally.

Re: the Question of better care by the physician as a result of participation in the HPIT Project: I don't know if he is even aware of it. He has never mentioned it nor has anyone in his office. I apologize for my lack of knowledge. Had I been aware of what was supposed to be going on the last 2 years I would have been glad to co-operate fully! P.S. The subject of this is healthy, very happy, very smart and darling beyond belief!

This has not affected our lives at all, she is a normal healthy 9 mo. old term girl. She had a tough start but she's perfect now. We already received excellent care from our pediatrician. This is the first we've heard of this since her birth.

I don't feel the program has made any difference in our case. I think this maybe due to a lack of follow through by the doctor more than a problem with the program. I also changed doctors when Sarah was around a year old so that could also be the problem.

As I recall the literature I was given about HPIT during my new babies illness seemed to befuddle me and my spouse.

I realize that the HPIT project is much needed and warranted in many instances but in my case I felt pressured by hospital staff to sign. In fact I refused to sign but they called me at home after discharge and strongly encouraged my verbal okay over the phone. I would have made follow up our number one priority regardless and the program has made no difference. Our follow up has been meticulous since birth for 18 months. My child had a single seizure at 2 days old, has had none since, is off medicine and has no defects in development. I'm a highly responsible person and felt it was a waste of state time and money, spending unnecessary time with our case when a more needy family could benefit more. I realize if my child had continued problems or defects as a result, my story might be different but as it is I fail to see any observable benefit from the program. Thank you for letting me voice my opinion.

My daughter has received the same care as my other child with regular check ups regardless of the HPIT Project. She had an infection at birth which is cleared and she is healtny. I don't feel there are any long term effects but I don't mind the HPIT Project just to make sure, I'm a little confused because I'm not aware of any extra care or cnecking due to having her on a list of HPIT infants. I've never been contacted and as I said I treat her like I would any of my children and would always get to a doctor if she was ill.

At first I was insulted by the suggestion that I take part in this program--it seems to be aimed or intended for women who do not take care of their baby's health, who may be more apt to neglect or abuse their children after birth, or at least would not maintain a routine health care program. I didn't feel I fit into that category. In fact, although my daughter has continually had problems with ear infections, her overall health and developments seem to surprise her physician.

I find no difference in health care between my infant and my 20 month old with the same problem. This might be due to high involvement of the staff in my county so I feel the program may be beneficial in other places.

COMMUNITY HEALTH NURSE/HOSPITAL NURSING STAFF/
PUBLIC HEALTH DEPARTMENT COMMENTS

I would like to see the following changes in the High Priority Infant Tracking Project:

I think that parents need some sort of feedback to maintain their level of commitment to participate in the program.

Best value as far as patient care is concerned is for the occasional mother who sees the "duty" to get the data filled our periodically as a motivation to continue regular well child visits.

Tighter criteria for admission to tracking the program is "pushed" so many infants are tracked who are "normal" or well established in the health care system.

Drop the 3-4 month tracking time.

Complete the procedures manual for use available before beginning system: have fewer periodic checks: clearer referral criteria-not general-social, environmental: specific written criteria same throughout project.

Drop 3 month tracking and add 4 year and 5 year tracking.

More feedback and meetings with the hospital by state and university staff.

Revision (e.g.: Deletion or expansion) of criteria: clearer definition of "high risk" as opposed to "moderate risk."

PHYSICIANS COMMENTS:

I would like to see the following changes in the High Priority Infant Tracking Project:

Prioritizing in the field of care of children should should include reducing the amount of paperwork involved so that service to these children can be directed and increased.

Teach physicians to help families do their own tracking. Medicine will never get anywnere until physicians quit playing God or Daddy and start helping people take responsibility for themselves and show them how! I would suggest training and supporting PNP's to be family nurse for families with handicapped or potentially handicapped children. Nurses do a better job of teaching at less cost.

I cannot see that the program has had any real impact on the patients I follow.

I have had no follow-up on whether HPIT has produces any better follow-up on patients. I dutifully send in the forms, but have no feeling of whether those forms help patients. I do think follow-up is critical, however, and certainly endorse the concept. Better communication back to physician is needed.

I wisn the envelopes were self addressed and stamped. Sometimes I would get as many as 10 forms to send at one time.

It helped me track patients, together with high risk or patients who had not been seen in a while, I had to pull the records to see if they had seen me or not. I highly agree with using this system in Pierce County. I pick up a lot of infants who had not followed or fallen through the cracks.

If you could take the medico-legal pressure off the deliver of health care in the OB's area I would be glad to lend every support of what proves to be worthwhile in this area.

Too many "conditions" identified and too frequent scheduled tracking forms. Accumulative effect is burdensome, although individually forms are easy to complete.

WASHINGTON STATE HIGH PRIORITY INFANT TRACKING PROJECT

STATE ADVISORY BOARD MEETING

Washington State Legislative Room: Thirteen Coins Building

Seattle, WA

May 22, 1986

PURPOSE: The Washington State High Priority Infant Tracking Project State Advisory Board met to: 1. Hear updated information regarding the data analysis report completed on 3-1-86. 2. To review and give direction to the project regarding revision of the Identification criteria and the Tracking process. 3. Receive reports regarding the Task Force Commitees formed last year. 4. Review the Program Evaluation activities of the HPIT Project to date.

ATTENDENTS: Jean Kajikawa, Fran Moellman, Nancy Smith, Joan Gaetz, Kathleen Eussen, Karen Holt, Bobbie Evans, Jerry Sells, Durlyn Finnie, Deboran Padgett, Robert Shertz, Mary O'Mara, John McLaughlin, Kathy Chapman, Patti Biro

Guests: Aleta Jesperson, Carol Weiss, Arleta Erickson

* See attatched list of State Advisory Board Members and State Staff.

I.

MINUTES:

Call to Order: Dr. Jerry Sells called the meeting to order at 9:20 AM. Dr. Sells introduced the members and guests attending.

II.

Project Background:

Dr. Sells provided a brief history of the HPIT Project, and it's relationship to the follow-up program for NICU graduates from University Hospital. A multi-disciplinary task force coordinating the efforts at follow-up from Children's Hospital and Medical Center, University Hospital, and the State of Washington Office of Parent-Child Health Services proposed the initial pilot study in Whatcom County. The project was initially modeled after the tracking System in

North Carolina.

III.

Data Analysis Summary Report:

Patti Biro presented information contained in the Data Analysis Summary Report covering the period from 10-1982 to 03-86. The slide show presented today highlights the progress of the project to date, and has been presented to many groups during the last project year. A list of the presentations during the current year was given.

IV.

Proposed Changes in the Identification Criteria:

A. Inclusion of Less than 3 Pre-natal visits as a maternal health concern.

B. Inclusion of maternal history of a communicable disease, such as Hepititis B or AIDS.

C. Reduction in the Low Birthweight Criteria to < 2000 Grams.

D. Elimination of Head Circumference as an High Priority Indicatory.

E. Quantify the Intracranial Hemorrhage Criteria by including a grade, (e.g. > Grade 2).

F. Inclusion of an expanded version of Clinical Impression of Possible Neurological Abnormality.

G. Inclusion of Significant Repiratory Concerns.

H. Elimation of Hyperbilirubinemia.

I. Combine all congential and acquired infections, and add AIDS to the list.

J. Expansion of information related to Risk Factors for the Visual and Hearing Impairment categories.

K. Revision of the Environmental/Social and Parenting Risk Factors, to highlight specific Parenting Concerns from Environmental/Social Concerns.

DISCUSSION/DECISIONS:

Topics A. and B. were discussed and recommended for inclusion. The birthweight criteria was discussed. A possible further reduction to 1500 Grams was discussed. It was felt that a reduction to 2000 Grams at this time was appropriate, and as further information becomes available, the weight may be lowered again. Topic D., Head Circumference was discussed. It was recommended that the revised criteria include OFC less than or equal to the 3rd percentile to continue to identify children with microcephaly. Intracranial Hemorrhage will not be revised. Topic F. related to possible neurological abnormality was discussed and was recommended for an expanded definition on the back of the identification form. Repiratory concerns were discussed and due to the large number of infants already identified with these problems, will be included on the revised forms. Hyperbilirubinemia was slated for elimination. It was felt that this could be included in the "Other Medical Concerns" category if warranted. Topic I. and J. were discussed and approved. After a great deal of discussion the Environmental Social and Parenting Risk Factors will be separated, and will be left as blank lines for the person completing the form to fill in. Guidlines regarding the identification of these risk factors will be included the procedures manual for further clarification.

Proposed Changes in the Tracking Process:

A. Elimination the 3-4 month Tracking Period.

B. Elimination of the "in treatment" section of the form.

C. Inclusion of community services the infant and his/her family may be using in a check off format.

D. Inclusion of "Acute Care Only" to the Under Care Question

E. Modification of "Failure to Thrive"to "Poor Pattern of Weight Gain"

F. Modification of the the word "Major" health concern to "Significant"

Discussion/Decisions:

A. Discussed and slated for elimination. A letter to parents will be sent at this time to welcome parents to the program, and encourage them to return to their physician for a the six month check-up.

B. Discussed and slated for elimination.

C. Highly recommended to save time for the physician and the person(s) reaponsible for mailing the form from the health department. It will be added to the revised form.

D. Discussed and recommended for inclusion

E. Discussed and recommended as a less"negative" and "judgemental" method of recording a growth concern.

F. Discussed and recommended as a modification.

Additional: A letter to parents at 30 months of age is recommened to encourage the parents to return to their physician for the 36 month check up, to inform them that the tracking program is ending for their child, and to provide information for the parents regarding child find activities and school services. The pamphlet "Rx for Childfind" will be included in the 30 month mailing.

**The meeting was temporarily adjourned for lunch at 12:20 until 1:30 PM

V.

Task Force Update:

Kathy Chapman reviewed the progress of the three Task Force Committees during the last project year. The minutes from each of the three committees were mailed to all advisory board members. The Procedures Manual is complete and was available during the meeting for members to review. Discussion related to Open Enrollement was moderated by Ms. Chapman. At this time the board does not recommend open enrollment, due to limited resources, and other priorities.

VI.

Discussion:

The membership discussed several recommendations brought forth by Dr. Sells. It was discussed and recommended that the HPIT Project be continued, and that the Board should advocate for state-wide adoption of the project. A letter will be forthcoming for all board members to sign regarding this proposal. The board has decided to remain intact as an advisory board, and to meet again next year in May. The project is currently funded until 6-30-86. Additional funding from grant sources, foundations and other programs

will be explored. Several counties have expressed interest in the HPIT Project; Grays Harbor, Clallam, and Snohomish. The feasibility of including these counties will be explored.

Further dessemination of the project is planned. This will include national presentations of the project, as well as intensive coverage in the state. A packet of information will be mailed to all health departments in the state.

The meeting was adjourned at 3:00 PM

HIGH PRIORITY INFANT TRACKING PROJECT
January-1986

PROCEDURES MANUAL

CONTRIBUTORS

Mary Allen

Patricia Biro

Jan Danl

Karen Holt

Sue Hyndman

Aleta Jesperson

Melinda Knutson

Christine Nelson

Deborah Padgett

Theresa Westerberg

Steven Wisner

*This project is supported by the State of Washington Parent and Child Health Services Division of the Department of Social and Health Services. In coordination with the University of Washington the High Priority Infant Tracking Project has been successfully implemented in Whatcom and Thurston Counties.

HIGH PRIORITY INFANT TRACKING PROJECT

PROCEDURES MANUAL

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INTRODUCTION

In October, 1982 the Washington State Parent and Child Health Services, in coordination with the University of Washington, implemented the High Priority Infant Tracking Project as a pilot project in Whatcom County, Washington. To further evaluate the effectiveness of the tracking system, Thurston County, Washington was added to the pilot project as a matched project in May, 1984. The primary objectives of the project are as follows:

1. To help parents keep their child under the care of a primary physician.

2. To promote early identification of infants requiring further evaluation, or services.

3. To help in planning for the health and educational needs of the children of Washington State.

The program is initiated by first identifying high priority infants according to "high priority" indicators listed on the IDENTIFICATION FORM. The IDENTIFICATION FORM is then completed, including obtaining consent from parents and the infant's primary health care provider. A copy of this form is then sent to the public health department, and enrollment into the tracking system is completed. A TRACKING FORM is sent to the infant's primary care provider at three months, six months, twelve months, eighteen months, twenty-four months, and thirty-six months. This form includes questions regarding the infant's health and developmental status, use of community services, and whether or not the infant is still receiving ongoing health care. If the health care provider indicates the infant is not receiving care, the public health nurse attempts to locate the family and reconnect them with the health care system.

PROJECT COORDINATION

The High Priority Infant Tracking Project is a program of the Washington State Department of Health and Social Services, Parent and Child Health Services Section. In coordination with the University of Washington the state provides consultation, leadership and financial support for the project. Project personnel at the University of Washington provide technical assistance, data management, consultation, and administration of the project. At the local community level the activities of the project are coordinated by local health department. Community hospitals, health clinics, and health care providers in each community work together at the local level through the coordination of the health department.

BENEFITS OF A TRACKING SYSTEM

An organized and coordinated tracking system which is implemented through local health care providers, the local health department, and community hospitals can provide the community with improved health care follow-up for high priority infants. Such a system can additionally...

--ensure that high priority infants have access to health care services in their local community.

--provide an effective and timely system for referral to other services the child or his or her family may require, such as Crippled Children's Services, supplemental food programs, or local school district services.

--help to integrate and coordinate health care for high priority infants and their families.

--create linkage between local hospitals, the health department and health care providers.

PROCEDURES FOR IMPLEMENTING THE TRACKING SYSTEM
IN A NEW COUNTY

INTRODUCTION

When a new county is to be added to the Tracking Project the following steps should be followed. They are arranged to be followed in a chronological sequence.

PRE-IMPLEMENTATION PROCEDURES

General Procedures;

Step 1. A. When a new county demonstrates interest in the HPIT Project, an initial contact can be made to tne HPIT Project Coordinator or a state MCH Nursing Consultant.

B. If another state wishes information regarding the HPIT Project, the state Nursing Consultant should make the initial contact.

Step 2. A. A liaison should be established who represents a local health or education agency to serve as the HPIT Project Coordinator fo that county.

B. An additional liaison person connected with the community hospital system is advised. This person may be the Pediatric Chairman, or the Medical Director of the Nursery. In addition, this person should also be asked to join the Local Advisory Board at a later date.

Step 3. A. Coordinated communication between the state nursing consultant, tne HPIT Project Coordinator and the local liaisons should occur to explain tne HPIT project, Goals and Objectives, time requirements, expectations, financial concerns, and possible outcomes.

B. A community meeting/information session may be needed at this time to determine the feasibility of implementing the program in the local community.

Step 4. If the decision is made to implement the program, HPIT Project Coordinator, State Nursing Consultant, and the local liaisons, the medical directors of each community hospital should be contacted in the following manner:

A. in written form prior to an in person meeting to solicit support for the project and to provide introductory information.

B. in person, to answer questions and to determine each hospital's unique confidentiality requirements, human subjects policies, or research review board procedures.

Step 5. For each participating hospital the procedure for application may vary. It is critical to determine the approved policy for each hospital and follow that procedure accordingly.

Step 6. Concurrent to, or immediately after the application process is initiated, additional informational meetings may be scheduled to:

A. solicit support and enthusiasm for the project.

B. share information regarding the goals and objectives of the HPIT Project and its benefit to the community.

C. solicit potential members for a local advisory board.

D. establish lines of communication between HPIT Project personnel at the state and university levels, the local health department, and/or coordinating agency, educational service providers, hospitals, and health care providers.

TARGET GROUPS FOR INFORMATIONAL MEETINGS

The following groups within the local community should be approached to schedule an information meeting.

1. Maternal-Child Health Division staff from the health department and the hospitals, nursing administrators, hospital administrators, including medical records staff, labor and delivery, post-partum, and nursery staff and administrators in each hospital. In addition social services staff in each hospital should be targeted.

2. Medical personnel including family physicians, pediatricians, OB/GYN specialists, and general practice physicians, and nurse practitioners.

3. Local County Commissioners, and other community volunteer or appointed commissions which may be interested. (An example might be a volunteer Health Department Advisory Board.)

4. Local School district representatives, such as Special Education Coordinators, or the Early Childhood Coordinators, as well as staff members who may have a special interest and/or training in working with infants, such as physical therapists, communication disorders specialists, or occupational therapists. Parents and educators from the local Parent-Teachers Association should also be targeted.

5. Local social service agencies, health clinics, or other agencies which may serve high priority infants and their families.

6. Local infant day care, infant stimulation programs and Head Start Program providers.

7. Local consumer advocacy groups, such as Parents of Prematures.

8. Local Neuromuscular Centers, or other centers which provide therapeutic services to infants.

9. United Way Board Members, or representatives from United Way Agencies.

10. Local March of Dimes members, United Cerebral Palsy members, and the local Association for Retarded Citizens.

With all the groups who participate in a informational meeting the following information should be shared:

A. Copies of the Identification and Tracking Forms

B. Parent Brochures

C. General Information Brochures

D. Recommended Procedures for Identification and Tracking

E. Data Summary Reports from other counties if appropriate

F. Local demographic information regarding the numbers of infants born in the county, past systems of follow-up etc.

SOLICITING MEMBERS FOR A LOCAL ADVISORY BOARD

At the close of each informational meeting the plans for the development of a local HPIT Project Advisory Board should be shared. Potential members should be solicited from the target groups. Broad representation from the health care and educational fields is encouraged. Local members have a responsibility to attend meetings and report to their agencies regarding the progress of the local program. These persons are a critical link between the program, health and education services providers and consumers in the community.

PRE-IMPLEMENTATION

HOW TO DEVELOP A LOCAL ADVISORY BOARD

PREREQUISITES: Prior to establishing a local advisory board for the HPIT Project the following pre-requisites should be met:

1. the local coordinating agency has been determined, this may be the local health department, school district or other agency.

2. in person consultation has occurred between the local health/education liaisons, hospital liaisons, state MCH Nurse Consultant and the HPIT Project coordinator.

3. informational meetings have been held in the community to assess community interest and support for the project.

POTENTIAL BOARD MEMBERS

Potential local advisory board members should reflect an integration of personnel and agencies professionally and personally with infants and young children. The fields of education, medicine, nursing, social services, and other health care or service related professions should be represented. Parents are also recommended as potential members of an advisory board.

The recommended number of members is twelve to fifteen people, with one or two alternates. The membership of alternates is especially important. If an agency wishes to participate on the board, one member and one alternate may be chosen from that agency. This will help to ensure that the agency will be represented at meetings even if the primary member is unable to attend.

SOLICITATION OF POTENTIAL BOARD MEMBERS

Potential board members may be solicited at the informational meetings. It is recommended that potential board members apply to the local liaison. Potential members should be informed of their expected responsibilities as advisory board members.

RESPONSIBILITIES OF BOARD MEMBERS

Local advisory board members serve the HPIT Project in their community in three ways;

ADVOCACY: Local advisory board members should be advocates for the HPIT Project and for better health and educational services for young children in general.

COMMUNICATION: Local advisory board members are expected to share information regarding the HPIT Project with the agencies or groups that they represent.

CONSULTATION: Local advisory board members provide valuable input into local decision making and provide guidance for the HPIT Project in their local community. They provide important feedback to the HPIT Coordinator and the State of Washington Office of Maternal-Child Health Services.

The three functions of an advisory board members are to advise, inform, and stimulate the HPIT Project at the local level.

MEETINGS

An initial information meeting should be held for all potential board members. At the introductory meeting the materials which were shared in the informational meetings should be shared, and any questions answered. It is recommended that either the state MCH Nurse Consultant or the HPIT Project Coordinator be present to answer these questions. In addition, the responsibilities of an advisory board member should be shared verbally and in writing. At this time potential members may decide to participate or to withdraw.

MEETING TIMES:

Specific meeting times may be decided at the introductory meeting. It is recommended that the local advisory board meet more often in the initial implementation stages of the HPIT Project in the local community, perhaps as often as four or more times in the first year. After the project is better established bi-annual or annual meetings of the board may be sufficient.

ATTENDANCE:

Attendance is an important responsibility of a potential advisory board member. The number of anticipated meetings per year should be shared at the introductory meeting.

ELECTION OF AN ADVISORY BOARD CHAIRMAN:

It is recommended that at the first formal meeting of the local advisory board an advisory board chairman be elected by the membership. The responsibilities of the Chairman are to:

1. monitor the progress of the HPIT Project in the local community (to take its pulse).

2. serve as an advocate and spokesperson for the project in the local community.

3. help facilitate completion of the project goals (to oil wheels when things get stuck)

4. share information regarding the local HPIT Project with others who show interest.

5. serve as a liaison for the HPIT Project Coordinator and the state MCH Nursing Consultant.

6. coordinate and monitor sub-committees or special interest groups that the advisory board may wish to develop.

LOCAL ADVISORY BOARD OBJECTIVES

The objectives of the local advisory group might include the following:

1. to increase the community visability of the HPIT Project.
2. to become informed about the HPIT Project in other communities.
3. to aid in the development of a marketing plan for the local community.
4. to assist in determining the cost/benefits of the program in the local community.
5. to explore and determine what policies and programs currently in place in the community are related to the objectives of the HPIT project.
6. to provide ongoing direction and decision making on policies and changes in the program.

Other objectives may be developed by the local advisory board as needs arise, or in response to suggestions by board members, or sub-committees.

PRE-IMPLEMENTATION ACTIVITIES

LOCAL HEALTH DEPARTMENT OR COORDINATING AGENCY

The following steps are arranged in chronological sequence and are designed to demonstrate the process at the local health department or coordination agency in the Pre-Implementation Phase of initiating the HPIT Project. The coordinating agency can be the local health department, education services district, or another agency which can serve infants and parent on a county wide basis.

STEP 1. Identify local community hospitals which may serve as identification sites for the HPIT Project.

STEP 2. A. Implement the Procedures for Adding a New Hospital or Identification Site for each hospital identified.

B. Determine who will be responsible for providing clerical support for the HPIT Project. This person plays a critical role in the day to day management of the project and it's overall success.

STEP 3. Set up a TICKER CARD system for the HPIT Infants for use during the Tracking period.

A. Clerical or support staff who are responsible for the HPIT Project should become familiar with the goals and objectives of the program, and the Identification and Tracking Forms.

B. As each new HPIT Project referral (ID form) enters the agency system it is entered onto a master file, containing the infant's name, address, parental information and primary health care provider's name and address, as well as any health department services the child or his or her family is receiving (WIC, CCS, etc.). A copy of the ID form is kept on file at the agency. If the copy which goes to the University of Washington has not already been forwarded, it is done now.

C. A separate file system is started for HPIT infants.

This system consists of a card for each infant and a file system by month for the tracking periods.

EXAMPLE

CARSON, ROSE LEE
B.D. 08/01/83

01-0000000001 (hospital number)

mo. Caren Carson
fa. Lee Carson

2400 E. College
Lacey, WA 98003
232-9987

due	mailed	returned	disposition
11/83	11-2-83	11-20-83	
02/84	02-1-84	02-21-84	*acute care only
08/84			
08/85			
08/86			

Fred Geer, M.D.
400 N. Thurston
Olympia, WA 98506

D. The Tracking Forms should be mailed to the physicians or health clinic before the child actually reaches the tracking period, so that the form can be completed by the physician when he sees the child.

E. When the Tracking Form is returned, it is noted on the Tickler Card, and the card is then re-filed according to the month of the next tracking period. The disposition of the case should be noted, such as second mailings, a change to a new health care provider, or a change in status, such as acute care only, to facilitate appropriate follow-up.

F. At the beginning of each month those infants requiring Tracking Forms to be mailed to the primary care provider are pulled.

G. The Intervention Services portion of the Tracking Form is completed using information obtain on the master file. Additional information gained from the return of previous forms may also be recorded. The physician's office should review this information with the family and record any additional services.

** This step is recommended because the provision of this information is a.) a service to the primary care provider and b.) enables the care provider to inquire if further services are needed.

H. Tracking Forms are then mailed from the health department to the local care providers.

I. The Tickler Cards remain in the file until the form is returned.

J. When a form is returned, the Tickler card is refiled according to the month of the next tracking period.

K. If a Tracking Form is not returned before the beginning of the next month a telephone call is made to the primary care provider. Generally his or her nurse or office secretary will follow-up on this reminder. If necessary another form will be mailed out. Mark on the tracking form that this is the second request. Red ink is recommended. Record this information on the tickler card in the "Disposition" section.

L. If a form is returned which indicates that the infant has not been receiving health care, the form may:

1. be forwarded to the new primary care provider.

2. be forwarded to the local health department HPIT Coordinator who then attempts to reconnect the family with the health care system.

3. if the child has only received acute care during the tracking period the family is contacted to ensure that they return to their provider for a well child visit. In some cases the well child clinic within the local health department may be used for routine well child care, in coordination with the primary care provider for acute illness care.

M. If the family cannot be reconnected with the health care system after a telephone call, letter and home visit, the case is closed and this is noted on the tickler card.

N. If the family reconnects with the health care system, the card will be refiled upon receipt of a completed Tracking Form.

1. When a family does not make contact with their primary health care provider, a flagging system may be used to alert other health department services that the infant is enrolled in the HPIT Project and is in need of a well child check up. Through this process, a child who may come to the health department for immunizations may be encouraged to return to care with the local primary care provider. A sticker denoting enrollment is placed on the child's master chart within the local health department or coordinating agency.

2. Information regarding the use of intervention services should be updated at 6 months, 18 months, and 36 months.

STEP 4. An introductory letter may be mailed by the local agency HPIT Project Coordinator/Liaison and the local hospital liaison to the local health care providers.

A sample letter is provided.

SAMPLE LETTER TO HEALTH CARE PROVIDERS

DATE

TO: (County) Physicians

FROM: Local Agency HPIT Coordinator/Liaison
Local Hospital Liaison (M.D.)
Address

SUBJECT: High Priority Infant Tracking Project

The Washington State Maternal and Child Health Services Program, in coordination with the University of Washington, and a statewide advisory board with representation of physicians, medical specialists, and hospitals is seeking to implement a High Priorty Infant Tracking Sytem in Washington State. This is in response to a need increasingly expressed by health care professionals including those from _____ County, for a method to ensure the provision of necessary service to at-risk infants following hospital discharge. The proposed system has as its primary objective the maintenance of potentially vulnerable infants within the existing health care system, where early detection of health or developmental problems can occur and treatment be initiated.

The HPIT Project has been pilot tested in both Whatcom and Thurston counties. Data has now been collected for three years in Whatcom County and almost two years in Thurston County. The reported findings indicate that the HPIT Project is successfully meeting its objectives.

_____ County is seeking to implement the HPIT Project in our community. We would like to encourage your participation in this worthwhile program. The success of the program will depend on community physicians' willingness to obtain parental consent for the enrollment of their infant into the program and to complete the tracking form at regular intervals. For your information, we have enclosed copies of the Identification Form, Tracking Form, and the parent brochure. We hope you will be able to attend an informational meeting regarding this exciting project in our community.

enclosures

SUGGESTED PROCEDURES: ADDIING A NEW HOSPITAL/OR IDENTIFICATION SITE

STEP 1. When adding a new site, the initial contact should be made by the Tracking Project Coordinator, and/or tne local agency HPIT Project liaison.

The hospital nursing supervisor, or the Maternal-Child Health Nursing Supervisor who would have primary responsibility for the program should be contacted to explain the HPIT project, goals and objectives and how the hospital or birthing center could be served by participation in the project.

Initial contact may be via telephone.

STEP 2. Request an appointment to meet with the nursing supervisor, nursing adminstrator, or MCH supervisor. Also request that tne Medical Director of the hospital and/or administrator be present at this meeting. A member of tne advisory board may be included if appropriate.

At this contact, explain the program; providing examples of the ID form, the parent's brochure, and other information which may be of interest, such as summary reports.

At this contact, determine the hospital's procedure for participation in a new program. Information may need to be shared with a Human Subjects Review Board, or a Research Committee before participation in the project can begin.

At this point it is critical to determine WHO needs to be contacted in the future and what the offical chain of command is for that particular hospital.

STEP 3. Determine who will serve as the HPIT liaison for the hospital. This may be a hospital social worker, or the MCH supervisor or a head nurse from Nursery or NICU, or his or her delegate. The HPIT liaison may be someone who has a special interest in high priority infants and health care follow-up.

STEP 4. When the appropriate authorization for participation in the project is secured, a request to provide an inservice is made.

Inservice training for the HPIT Project should include nursing staff from Labor and Delivery, Nursery staff, and staff from Mother-Baby units, and Post-partum staff.

STEP 5. Contact the local HPIT Coordinator from the health department or coordinating agency. Notify them of the upcoming inservice and request their participation.

STEP 6. Assign the new hospital/ID site a code number (two-digits) for coding and tracking purposes.

STEP 7. Conduct the inservice. The same inservice may have to be repeated to make contact with all shifts. At the initial inservice to the staff the presentation should be made by the HPIT Project Coordinator in coordination with the local agency HPIT Project Coordinator/Liaison.

STEP 8. Supply the hospital or ID site with ID forms, parent brochures, general information brocnures, and a copy of the Procedures Manual.

STEP 9. Follow up the inservice with a telephone call 2-3 weeks after the first inservice to determine any further need for information or assistance.

It has been recommended as a "best practice" to select one person per shift to be the HPIT person in charge of referrals.

STEP 10. It is recommended as a "best practice" that the local HPIT Project Coordinator/Liaison pick up the completed forms once or twice a week depending on the number of births for that hospital. An arrangement should be made with the head nurse, or the person responsible as the hospital liaison for the project for collecting forms.

**

This is recommended as a best practice in order to facilitate ongoing communication and provide informal inservice to the hospital.

STEP 11. The local health department HPIT Project Coordinator/Liaison may contact the hospital or identification site approximately every two months to determine if additional supplies/forms are needed. An alternative arrangement can be made to have the hospital liaison telephone when supplies are needed.

STEP 12. Complete HPIT Project IDENTIFICATION FORMS are then dissemminated as instructed; (other than the white copies which go to the local health department).

the goldenrod copy remains in the hospital either in the infant's medical chart or in a nursery log.

the pink copy of the form is forwarded to the doctor.

the canary copy is forwarded to the University of Washington for data analysis **NOTE--this copy contains no personal information--only the hospital number and identification information.

PRE-IMPLEMENTATION PROCEDURES

RECOMMENDED PROCEDURES TO DETERMINE THE INCIDENCE OF HIGH PRIORITY INFANTS IN THE COMMUNITY

An initial review of the vital statistics data for a county over a one year period can provide information regarding the actual number of births for the county and a projection of the possible numbers of high priority infants. This information may be obtained through consultation with the MCH nurse consultant. Additional procedures recommended in the Pre-Implementation phase of the HPIT Project are chart review and pre-pilot study. Chart review is recommended prior to the implementation of the project and also an ongoing evaluation activity. The second procedure, a Pre-Implementation Study may or may not be implemented to determine the healthcare dropout rate, developmental and health status of high priorty infants in the local community prior to the implementation of the HPIT Project.

CHART REVIEW:

Chart review of infants, and possible maternal charts is an important process in determining the status of high priority infants in the local community, and also to determine how successful each hospital is in the correct identification of high priority infants after the project is implemented.

RECOMMENDED PROCEDURES FOR CHART REVIEW

STEP 1. Determine who will be responsible for conducting the chart review. This may be the local HPIT Coordinator, the hospital HPIT liaison, or some other designee. More than one person may be used. The HPIT project coordinator, or the state MCH nurse consultant may coordinate the first chart review in a new community.

STEP 2. Obtain the necessary permission to conduct chart review from each of the participating hospitals.

STEP 3. Become familiar with the Identification Criteria as reported on the IDENTIFICATION FORM.

See the copy of the CHART REVIEW FORM on the following page.

STEP 4. Determine the specific period of time to be covered in the chart review.

For a hospital with a small number of births, a reviewer may choose to review all the charts for a one year time period. For a larger hospital a percentage of all birth charts, such as 10%, may be reviewed for a one year period.

STEP 5. Upon completion of the chart review process for each of the hospitals that will be participating in the HPIT Project, a determination of the ANTICIPATED percentage of high priority infants for each hospital, and the county can then be estimated.

** Remember, chart review yields only an estimation of the potential percentage of hign priority infants for a specific time period, for a specific hospital.

STEP 6. At this point, a pre-implementation study, such as the Thurston COUNTY PRE-PILOT STUDY may be indicated for a new community which is implementing the HPIT Project for the first time.

More information on tne procedures used in this study are located in the EVALUATION SECTION of this manual.

STEP 7. The use of chart review for ongoing program evaluation is discussed further in the EVALUATION SECTION of this manual.

HIGH PRIORITY INFANT TRACKING PROJECT CHART REVIEW INFORMATION

_____case number

_____date of birth_____gestational age (weeks)

_____sex infant born in this hospital?_____

if no, hospital of birth_____

_____

Inclusion criteria:

Comments:

_____

Time spent on chart review:_____

SECTION III

IDENTIFICATION PROCEDURES

A. Hospital Identification Procedure. 20

B. Physician Identification Procedure 23

C. Community Health Nurse/Public Health Physician Procedure 24

D. Local Health Department/Coordinating Agency Procedures . . 26

IDENTIFICATION PROCEDURES

HOSPITAL IDENTIFICATON PROCEDURE

The following steps outline the recommended procedure for the Indentification of High Priority Infants in the hospital setting. This information should be shared at all informational meetings prior to implementation and is a critical part of the inservice orientation to the HPIT Project for hospital personnel.

STEPS	KEY POINTS
1. The Identification Criteria used for identification of infants is found on the IDENTIFICATION FORM.	The charge nurse on each shift is responsible for knowing the identification of eligible infants.
2. When an infant is identified as High Priority an IDENTIFICATION FORM needs to be completed. The top two sections should be completed witnin tne first day after tne cnild is identified. (Each nospital has a two digit code number, this is followed by the infant's hospital number. This section contains the infant's name, address, parent's name and identification criteria.	The IDENTIFICATION FORMS should be located in specific place in tne nursery. Be sure the infants hospital number is correct and is preceeded by the hospital code number. Example: 20-0983652
3. After tne infant is identified and tne top portion is completed, including tne identification criteria, sign your name and date tne form.	The date following the signature under "Form completed by" must be within 30 days after tne infant's birthdate unless otnerwise noted.
4. If tne infant is transferred to another hospital, attach the IDENTIFICATION FORM to the transfer papers with tne HIGH PRIORITY INFANT TRACKING PROJECT Information and Instruction Sheet.	The admitting hospital is responsible for identifying high priority infants and completing the first half of the IDENTIFICATION FORM. However, the original admitting hospital should not obtain parental consent, or explain the details of the program. Tne completion of tne form should occur one or two days prior to discharge by the discharging hospital. This policy is made to prevent overwhelming parents with plans for future programs when their baby's outcome is uncertain (e.g. before transfer to a tertiary care center).

5. If the infant stays in this hospital proceed tnrough tne identification process. The next step is to contact the primary health care provider. The health care provider needs to provde written or verbal consent for enrollment in the tracking project.

Without this consent the infant cannot be enrolled. If verbal consent is obtained co-sign your name next to the health care provider's name.

*Be sure to share the ID Form with the physician, if possible.

6. Contact the infant's parent(s). Explain tnat their infant has been identified as High Priority, and that tney have tne option of enrolling their infant into a tracking program. Explain tne tracking process. Provide the parents with the Parent Brocnure. Allow time for them to read the brocnure and ask questions.

The parents should be told why their infant is High Priority. Parents should be told that participation is voluntary, that confidentiality is assured, and that the program is free. Explain tne state of Washington OMCH involvement.

7. OBTAIN PARENTAL CONSENT. Have the parent sign the IDENTIFICATION FORM, giving consent for their infant to be enrolled into the tracking project.

The infant will not be tracked unless the parental consent is signed.

8. Sign your name as witness.

9. Complete tne section indicating the amount of time spent on HPIT.

The section helps to evaluate the amount of time spent in the identification process.

10. Cneck the form for completion.

Is the infant's hospital number on the form?

Does the hospital code (two digits) preceed the number?

Is the infant's name on the form?

Is tne infant's birthdate, gestational age, and sex on form? Are the birthweight, and APGAR scores reported.

Is tne infant's address on tne form? Is it a _____County address?

Is the parent's phone number on the form?

Is tnere a second contact person on the form with an address and phone number?

Is tne motner's age on the form?

Is the primary health care provider's name and address on the form?

SUGGESTIONS:

1. A copy of the PROCEDURES MANUAL should be kept in a location where it can easily be referred to.

   As part of this manual, additional pages should be added for staff to write down questions to ask either the Local HPIT Project Coordinator, or other HPIT staff. Answers to these questions should also be recorded for future reference.

2. A current listing of the types of cases reported for each IDENTIFICATION CRITERIA should be a part of the hospital procedure manual.

   In cases of PARENTING, ENVIRONMENTAL, or SOCIAL RISK factors, case histories may be helpful to include. (Note, these should be hypothetical case histories to protect confidentiality.)

3. Rationale for and/or educational material regarding specific items may be included.

   For example: A collection of articles regarding risk factors for hearing loss may be kept in the procedures notebook. An article such as the "High Risk Register for Deafness"* may provide a ready reference for hospital staff.

*Gerkin, K.P. "The High Risk Register for Deafness" American Speech, Language and Hearing Journal, (26):3, 17-23, 1984.

IDENTIFICATION PROCEDURES

PHYSICIAN IDENTIFICATON PROCEDURE

A primary care physician may identify an eligible infant for the HPIT Project. Identification must occur during the enrollment period. (Currently witnin the first 30 days of life.)

The following procedure may be used in the case of a physician referral for the project.

STEPS	KEY POINTS
1. The phnysician identifies an infant who meets one or more eligibility criteria as noted on the IDENTIFICATION FORM.	Identification must occur during the eligibility period.
2. IDENTIFICATION FORMS are available upon request from tne Local Health Department HPIT Project Coordinator.	A copy of the parent brochure should also be obtained.
3. The physician completes tne IDENTIFICATION FORM noting e eligibility criteria.	
4. The pnysician explains the HPIT Project, obtains parental consent, and forwards the completed form to the local Health Department HPIT Project Coordinator.	

ALTERNATIVE PROCEDURE

After an eligible infant has been identified in the pnysician's office, STEP 1, the following alternative procedures may be followed.

2. A referral is made to the Local HPIT Project Coordinator.

   This request may be for a community healtn nurse or agency representative home visit to enroll the infant into tne tracking project.

3. Tne pnysician shares witn the family information regarding tne infant's eligibility, and referral to tne project.

* Tne alternative procedure should be used only wnen there are adequate resources for nome visits by the local HPIT Project Coordinator and staff. If not, the pnysician snould enter tne cnild into the system.

IDENTIFICATION PROCEDURE

COMMUNITY HEALTH NURSE/PUBLIC HEALTH PHYSICIAN PROCEDURES

An eligible infant may be identified and entered into the HPIT Project tnrough a Community Health Nurse (CHN), or a Public Health Physician (PHP). The following procedures are recommended for the Identification and entry of infants into the HPIT Project.

STEPS	KEY POINTS
1. Community Health Nursing staff and/or the Public Health Physician should be familiar with the IDENTIFICATION CRITERIA.	These criteria are located on the IDENTIFICATION FORM.
2. The CHN or the PHP may identify and enter an infant into the tracking project at any point during the eligibility period. (At this time it is tne first 30 days of life.)	Note the limitations of the eligibility period.
3. An eligible infant may oe referred from any of the following sources: --as a result of a CHN routine or requested home visit. --as a result of a referral from a primary care provider or health clinic. --as a result of a well child clinic held within the local health department. --as a result of a referral from an outside agency (such as CPS).	
4. When an infant is identified as High Priority the CHN or the PHP completes the IDENTIFICATION FORM.	Identification forms should be available in Well Child Clinic and for the CHNs.
5. The infant is given a CHN/PHP case number. This number is a two digit number to designate tne local health department, followed by a case number. Example: 07-0000023.	Check the form to make sure the case number has been added.
6. Contact tne infant's physician to obtain written or verbal consent to enter the infant into tne tracking project.	The infant cannot be tracked without the consent of tne physician.

7.	Contact the infant's parents either in a nome or clinic visit to explain the HPIT Project, answer questions, and obtain WRITTEN CONSENT.	The infant cannot be tracked without parental consent.
8.	Leave the Parent Brochure with the parents.	
9.	Sign your name as witness.	
10.	Complete the section on time spent for Identification.	This section helps to identify the amount of time spent in the identification of high priority infants.
11.	Foward the completed HPIT IDENTIFICATION FORM to the local HPIT Project Coordinator, who will forward them to the appropriate persons.	

IDENTIFICATION PROCEDURES

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCY PROCEDURE

The local HPIT Project Coordinator is responsible for the coordination of the IDENTIFICATION PHASE for the local hospitals, primary care providers, cooperating agencies and community health nurses. The following procedures are recommended to ensure a smooth transfer of information between the physicians, the hospitals, and the health department.

STEP 1. As each new IDENTIFICATION FORM is received a tickler card is made for that infant. (See the explanation of this system in the PRE-IMPLEMENTATION section of this manual.)

STEP 2. A letter of acknowledgement is sent to the referral physician, or if identification has taken place in the hospital a letter of introduction is sent to the infant's physician.

EXAMPLES OF THESE TWO LETTERS FOLLOW ON PAGES 32 AND 33.

STEP 3. A copy of the completed IDENTIFICATION FORM is mailed to the physician with the letter. (This is the pink copy) The participating hospitals may elect to forward the copies to the physicians.

STEP 4. Completed IDENTIFICATION FORMS are mailed in batches to the University of Washington for data analysis. Depending on the number of births for a given time, this may occur two or more times a month. Completed IDENTIFICATION forms may also be forwarded directly from the hospital if desired.

SAMPLE LETTER # 1

*To accompany ID Form, Pnysician referral

DATE:

TO: (Physician's Name and Address)

RE: (Infant's name)

Dear (Physician):

Tnank you for your recent referral to the Washington State High Priority Infant Tracking Project (HPIT).

HPIT is a developmental surveillance project which identifies and tracks high priority infants from birth to three years old. Only infants who are at an increased risk for developmental or health problems due to established, biological or environmental factors are eligiole for this service.

The HPIT Project has three objectives:

1.) To help parents keep their child under the care of a primary care physician.
2.) To promote early identification of infants who require further evaluation or services.
3.) To assist in planning for the health and educational needs of the children of Washington state.

The HPIT Project is strictly confidential. Only the health department or the coordinating agency and you will know this child by name.

On a regular schedule (3-4, 6-7, 12, 18, 24, and 36 months) you will receive a TRACKING FORM requesting information regarding whether the child is still under your care; and if so, what the child's current health and developmental status is. Information regarding the use of community/state services will also be collected. If the child has missed a well-child check-up, a community health nurse will attempt to contact the family and return them to your care.

The attacned IDENTIFICATION FORM indicates the condition(s), identified as being "high priority". You may add additional information, and return the form to me. If you have any questions regarding this patient, please feel free to contact me.

Sincerely,

community health nurse
or
agency coordinator

SAMPLE LETTER #2

*To accompany ID Form, first enrollee only, or when a physician has only a few infants enrolled in HPIT.

To: (Physician's name and address)

DATE:
RE: (Infant's name)

Dear Doctor_____,

Your client has been identified as a candidate for the Washington State High Priority Infant Tracking Project (HPIT).

HPIT is a developmental surveillance project which identifies and tracks high priority infants from birth to three years old. Only infants who are at an increased risk due to established biological or environmental factors for developmental or health problems are eligible for this service.

The HPIT Project has three objectives:

1.) To help parents keep their child under the care of their primary care physician.
2.) To promote early identification of infants who require further evaluation or services.
3.) To assist in planning for the health and educational needs of the children of our state.

The HPIT Project is strictly confidential. Only the health department and you will know this child by name.

On a regular schedule (3-4, 5-6, 12, 18, 24, and 36 months), you will receive a TRACKING FORM requesting information regarding whether the child is still under your care; and if so, what the child's current health and developmental status is. Information regarding the use of community/state services will also be collected. If the child has missed a well-child check up, a community health nurse will attempt to contact the family and return them to your care.

The attached IDENTIFICATION FORM indicates the condition(s) identified as being "high priority". You may add additional information, and return the form to me. If you have any questions regarding this patient please feel free to call me.

Sincerely,

_____
Local HPIT Coordinator

SECTION IV

TRACKING PROCEDURES

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Tracking Procedure

Re: Change in Recommended Procedures

The latest revisions in the Tracking Phase have been recommended and adopted as of July 1, 1986.

1. Elimination of the 3 month tracking form, previously mailed to the local primary care physician.

2. Initiation of a letter to the parent(s) of the enrollee(s) to verify enrollment, and the name and address of the primary care provider. See Sample Letter 2a.

This revision will be implemented immediately.

SAMPLE LETTER 2a

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCY

Letter to Parents at 3 months

Dear Parent,

Congratulations on the new addition to your family. You may recall that your son or daughter was identified for the Washington State High Priority Infant Tracking Project. We would like to welcome you to the program and answer any questions you may have regarding the project.

The objectives of the project are:

1. To help parents keep their child under the care of their primary physician.
2. To promote early identification of infants requiring further evaluation, or services.
3. To assist in planning for the health and educational needs of the children of Washington State.

Our records indicate the following information:

Health Care Provider _____

Address _____

_____

Telephone # _____

We encourage you to return to your health care provider for your infant's six month check-up. If you have changed health care providers please contact this office at (area code)_____-(telephone number)_____.

Please contact me if you have questions regarding the HPIT Project.

Sincerely,

Local HPIT Liaison

TRACKING PROCEDURES

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCY PROCEDURES

The local health department/or coordinating agency is responsible for initiating the TRACKING PHASE of the HPIT Project through the mailing of TRACKING FORMS to each child's primary care provider at the predetermined tracking periods. This is coordinated by the use of a TICKLER CARD system. The use of this system is discussed on pages 11-14.

Additional procedures involved in the TRACKING PHASE are covered in this section. These include: Local HPIT Coordinator Follow-up, Case Closure, and Transition/Termination of Tracking.

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCY

LOCAL HPIT COORDINATOR/COMMUNITY HEALTH NURSE FOLLOW-UP

The local HPIT Coordinator will review all completed TRACKING FORMS which are returned from the primary care providers. If further evaluation and/or services are warranted, the Coordinator will initiate the appropriate action required. If a child has not been seen by his/her primary care provider in a specific tracking period the following procedure is recommended for follow-up.

STEP 1. Initiate a log of infants who have not made contact with their care provider during the previous tracking period.

STEP 2. Attempt to contact the family through a telephone call. If you are successful, remind them they should return to their physician for routine well child care. Determine what the barriers are to returning the child to care and take appropriate action, such as an alternate source of health care.

STEP 3. IF YOU ARE UNABLE TO REACH THE FAMILY BY PHONE, OR THE FAMILY DOES NOT HAVE A TELEPHONE, a memo/letter should be mailed to the family with a copy of the letter to the primary care provider.

STEP 4. If there is no response to the memo, a home visit is necessary. It is recommended that a note/memo be sent to the primary care provider to inform them of the follow-up attempt.

STEP 5. If the family has moved, or you are unable to locate them, attempt to locate them by contacting the person(s) noted on the IDENTIFICATION FORM. These names, addresses and telephone numbers were provided at the time of identification to facilitate follow-up. A telephone call to the contact person, or a letter may be utilized to contact a family.

STEP 6. If none of the follow-up activities is successful, the case is closed. Often, a child can be traced through other health department services, especially if a flagging system as described on page 14 is used.

STEP 7. When a case is closed, a letter/memo is sent to the primary care provider.

STEP 8. Pull the child's TICKLER CARD. Note the date of closure, and file in the CASE CLOSED section of the card file.

STEP 9. Complete the CASE CLOSURE section of the TRACKING FORM, noting the reason and return to the University of Washington for data analysis.

STEP 10. A referral to Child Protective Services (CPS), may be advised in some cases. In these cases follow the local health department policy. A referral is made if the child is at serious risk of disability or injury due to established conditions if the continuity of health care is disrupted.

TRACKING PROCEDURES

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCY PROCEDURES

CASE CLOSURE

A case may be closed, and withdrawn from the TRACKING PHASE of the HPIT Project in the following situations: the child moves from the county/state, the child is lost to follow-up, parental permission is withdrawn, physician permission is withdrawn, the coordinating agency is unable to locate the family, or the child is deceased. In all cases the following steps are completed:

STEP 1. Complete the most recent TRACKING FORM Case Closure section.

STEP 2. Note the reason for the case closure and record the date of the case closure.

STEP 3. Foward the completed form to the University of Washington for data analysis.

STEP 4. Send a memo/letter to the child's primary care provider noting the reason for closure and the date of closure.

STEP 5. Pull the TICKLER CARD, note the date of closure, an refile in the CASE CLOSED section of the file.

TRACKING PROCEDURES

PHYSICIAN TRACKING PROCEDURES

The following procedures have been recommended as the sequence which may be followed in the primary care provider's office or medical clinic. They may be modified to suit the individual physician or clinic.

STEP 1. When an infant is entered into the tracking project the file copy of the IDENTIFICATION FORM is filed in the infant's chart as soon as it is received by the physician or clinic.

STEP 2. A self-adhesive sticker which denotes enrollment in the High Priority Infant Tracking Project is placed on the chart as a flag. (These are available in most office supply stores.)

STEP 3. A. As each TRACKING FORM arrives in the office the infants chart pulled, and the TRACKING FORM is attached to the chart.

B. The infant's recorded address on the tracking form should be checked against the current address of record in the physician's office. If a change of address has occurred, it should be noted on the tracking form.

STEP 4. The TRACKING FORM is then completed by the physician.

STEP 5. If possible the form is completed during or immediately after the infant's well child check up. If it is possible to complete the form during the visit, special attention can be paid to reporting the TYPE OF INTERVENTION SERVICES section of the TRACKING FORM.

STEP 6. Information recorded on the form should be related ONLY to that period of time since the previous TRACKING FORM. A copy of the previous TRACKING FORM should be in the file for review, or in the case of a newly identified infant, the IDENTIFICATION FORM should be available for review. If a problem was noted, but is resolved, it is not necessary to note it again.

STEP 7. A copy of the current TRACKING FORM should be left in the infant's file after completion.

STEP 8. The completed form is then forwarded to the local High Priority Infant Tracking Project Coordinator.

STEP 9. If the infant HAS NOT BEEN SEEN since the last tracking period, complete the top portion of the form, noting the date the infant was last seen in the clinic or office.

STEP 10. Foward the completed form as in Step 8.

*** When an infant has not been seen for well child care, the local HPIT coordinator will contact the family and assist them in returning the child to the physician's care.

TRACKING PROCEDURES/

TRANSITION PROCEDURES

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCY PROCEDURE

TERMINATION OF THE TRACKING PHASE

When a child has completed the full three years of the TRACKING PHASE the case is considered closed. The procedure below is designed to make the transition process smooth, and ensure communication between appropriate agencies.

STEP 1. A local resource list of agencies, school districts, and private or public therapists who offer services to preschool children should be developed.

STEP 2. A form letter such as the one that follows on page 41 should be developed using the local health department letterhead.

STEP 3. Prior to the first group of infants reaching age 36 months, a meeting may be called by the Local Advisory Group to discuss and develop a TRANSITION PLAN for those infants.

STEP 4. As a part of the TRANSITION PLAN, a meeting for all agencies serving preschool children may be organized to alert the agencies that children who are currently enrolled in the HPIT Project will soon be reaching age 3, and may require services.

STEP 5. With each 36 month TRACKING FORM, a copy of the resource list and the cover letter explaining the end of the TRACKING PHASE should be mailed.

STEP 6. Program Evaluation may be completed using a questionnaire. The use of questionnaires in program evaluation is discussed in the EVALUATION SECTION of this Manual.

SAMPLE LETTER #3 HEALTH DEPARTMENT/COORDINATING AGENCY

TO BE ATTACHED WITH 36 MONTH TRACKING FORM

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCY

TO: (Physician's Name and Address) DATE:

RE: (Child's name)

Dear Doctor _____.

Your patient _____ has been followed by the High Priority Infant Tracking Project since birth. The tracking project was designed to meet the following objectives;

1. To assist parents keep their child under the care of a primary physician.

2. To promote early identification of infants requiring further evaluation or services.

3. To assist in planning for the health and educational needs of the children in Washington State.

The project provides for tracking through age three. Your patient is soon to be three years old and this will be the final tracking form for this child. We appreciate your ongoing interest and support for this endeavor.

Research from the tracking system in Iowa has shown that approximately 20 percent of the biologically at risk infants born in a given year required either educational or therapeutic services in the early years. Of the remaining 80 percent, one fourth of those infants demonstrated emerging problems which required intervention at school entry. This research indicates that even children who do not demonstrate any clear health and/or developmental problems at this stage may show problems later in their school career.

Please remind your patients that they will no longer be followed by the High Priority Infant Tracking Projects. In addition please share the enclosed information regarding local resources for services, so that when concerns arise, the parent may contact the appropriate agency.

Again, your support has helped to make the High Priority Infant Tracking Project a valuable service for families in _____ County.

Sincerely,

Local HPIT Coordinator

encl.

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCY

SAMPLE TRANSITION PLAN

Resources: A resource file will be developed and an information brochure listing available resources will be developed by (date).

Information Exchange: A meeting to share information regading the HPIT Project and the needs of the children turning 3 years of age will be scheduled by (date).

Agencies to be invited to the meeting are:

Local Pnysicians.

Local School District Representatives

Local Head Start Director

Local Therapists/Special Educators, etc.

Parents

Notification: A letter to accompany each 36 month form will be developed for use by (date).

Evaluation: Physicians and parents who have participated in the project for the full three years will provide feedback to the project by completing a questionnaire at the end of the TRACKING PHASE.

SECTION V

PROGRAM EVALUATION

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An example: the Thurston County Pre Pilot Study

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PROGRAM EVALUATION

CHART REVIEW PROCEDURES

Chart review procedures is an important step in program evaluation for the High Priority Infant Tracking Project. This activity provides two important pieces of information; first, it permits an estimation of the number of high priority infants who potentially can be identified in a specific hospital or identification site, secondly, it provides a method of measuring the accuracy of the identification process within an identification site. The use of chart review to assess the success rate within an identification site can be effectively used to "troubleshoot" potential problems and increase the program effectiveness.

The chart review procedure may need to be modified to meet the needs of a particular hospital, or local health department. The following procedure outlines the method of chart review used in the High Priority Infant Tracking Project.

RECOMMENDED PROCEDURE

STEP 1. Determine who will be responsible for the chart review. This may be the local HPIT Coordinator, the hospital HPIT liaison, a staff nurse or social worker contact person.

STEP 2. If possible a team approach is recommended when conducting chart review for program evaluation. This is recommended to increase awareness of potential problem areas "in-house" as well as providing an opportunity for dialog regarding those potential problems.

A team approach can be used in two ways:

A. The team divides the number of charts to be reviewed, completing a CHART REVIEW FORM for each case reviewed. Upon completion of the chart review, the cases identified as eligible for the HPIT Project are discussed.

B. Each member of the team reviews all the charts selected for review. A CHART REVIEW FORM is completed for each case. Upon completion of the review all eligible cases are discussed by the team.

STEP 3. Obtain the necessary permission to conduct chart review from each of the participating hospitals or identification sites.

STEP 4. Determine the specific period of time to be covered for the chart review. For program evaluation this is recommended at least every six months during the implementation of the project. When a hospital or identification site demonstrates a success rate of 85-90% or better a decision may be made by the local HPIT coordinator, and the local hospital liaison, to review charts on an annual basis, or to review a smaller percentage of charts.

For a hospital with a small number of births, it may be reasonable to review all cnarts of infants born for the designated time frame. For a larger hospital, a percentage, such as 10% of all the charts of all infants born may be reviewed.

STEP 5. Notify the hospital or identification site of the time period selected for chart review and the number of charts to be reviewed (all or a percentage).

STEP 6. Schedule a time to review the charts.

STEP 7. Upon completion of the chart review process the team will meet and discuss the eligible cases identified. This will assure consistency in correctly identifying eligible infants based on the ID - Identification criteria and will provide information which may be used for later inservices to troubleshoot potential problem areas.

STEP 8. Determine the estimated percentage of high priority infants for that chart review.

EXAMPLE:

In hospital A. 10% of the charts for a six month period were reviewed. The number of actual births was 520. The number of charts reviewed by both members of the team was 52. From the group of 52 charts, 7 cases met one or more criteria for eligibility in the HPIT Project. This indicates that approximately 14% of the total births may be eligible for the project (7/52 = .1346). The projected number of eligible cases for the six month period is calculated in the following manner:

Total number of births:	520
	x .14
Estimated percentage of HPIT cases	
Potential HPIT cases	72.8

It is estimated that approximately 73 cases would have met one or more eligibility criteria for the HPIT Project during the six month period.

STEP 9. Determine the actual number of cases identified for the HPIT Project during the same time frame as the chart review. Include all eligible cases in this count. Cases not entered into the project but identified, should be included.

STEP 10. Calculate the projected success rate of identification by dividing the actual cases by the projected number.

EXAMPLE:

From the example above, 73 cases were estimated to be eligible for the HPIT Project. During this time frame, 54 cases were identified and/or enrolled in the HPIT Project.

54/73 = .7397 74% of the potentially eligible infants were correctly identified.

STEP 11. The chart review process yields an estimation of the POTENTIAL number of HPIT eligible cases for the specific time frame. It should be remembered that this is an estimation only.

A success rate of 20-30% is not unusual in the first year of implementation of the project in a new hospital.

A realistic goal is to increase the rate of successful identification over time. After two years of implementation the success rate should be 85% or better.

STEP 12. When a small number of charts are reviewed the cases who are eligible may be compared to the actual project case log. A list of the cases missed, and their eligibility criteria should be developed, and shared as soon as possible with the hospital or identification site staff.

STEP 13. In cases where an identified problem has repeatedly been missed, additional inservice for staff members responsible for completing the IDENTIFICATION FORM may be necessary.

PROGRAM EVALUATION

PRE-PILOT STUDY

The following procedures are from the Pre-Pilot study conducted in Thurston County.

A pre-implementation study will establish how many high priority children dropped out of health care prior to the establishment of a local teaching system, at what ages they dropped out, and what their health and developmental status was prior to drop out. This kind of study can be useful in convincing local participants of the importance and effectiveness of a tracking system. A tracking system should be able to keep 80-90% of identified children in the care of a primary provider. Without a tracking system 50-60% of children are lost to follow-up.

DIRECTIONS FOR THE PRE-PILOT STUDY-THURSTON COUNTY

The following directions are intended to facilitate the completion of the "Pre-Pilot Study-Thurston County." Each step should be completed and checked off as indicated.

Step	Date Completed
1. A chart review on all infants born from October 1, 1982 to April 30, 1983 should be done on infants residing in Thurston County and born at the following hospitals: - Children's Orthopedic Hospital and Medical Center (All Thurston County Births) - University Hospital - NICU (All Thurston County Births) - Tacoma General Hospital (All Thurston County Births) - Madigan Army Medical Center (10% of Births) - St. Peter's Hospital (10% of Births) High Priority infants should be identified, and their birthdates and primary care provider noted.	4/85
2. A hospital intermediary needs to be identified. This person should be familiar with the project, and have normal access to infant's charts. The list of high priority infants born during the pre-pilot period should be given to the intermediary. (S)he should keep this list in a secure place.	
3. The intermediary should then receive the following items:	

- A list of the numbers of Pre-Pilot Questionnaires to be sent to each identified primary health care provider (information should be provided by the person who completed the chart review).

- Pre-Pilot Cover Letters, with the correct name of the hospital, the physician, and the intermediary already completed. This can be done by having the number of infants per physician and per hospital known by the word processor personnel, so this information can be filled out for the intermediary. The envelopes with the physician's name and address should also be provided.

- The specified number of "Pre-Pilot Questionnaires." per hospital.

- The correct numbers of return envelopes to be sent to each physician. The return envelopes should have the University of Washington - Program Coordinator's name and address.

4. The intermediary then needs to enter the name of the high priority infants on the appropriate letter to each primary care provider. (S)he then needs to sign the cover letter. This letter needs to be sent to the primary health care providers with the correct number of Pre-Pilot Questionnaires (One questionnaire per infant) and a return envelope.

5. The primary health care provider then needs to complete one questionnaire per identified infant, and return the questionnaire in the provided envelope to the Program Coordinator.

6. The information from the questionnaires will provide data to assess the status of follow-up care in Thurston County before the "High Priority Infant Tracking Project" was instituted.

STEP BY STEP PROCESS USING ST. PETER'S HOSPITAL AS AN EXAMPLE: (1.) The chart reviews were completed in April, 1985 and seventeen infants were identified as having one or more of the high priority indicators. (2.) An intermediary should be assigned, and (3. & 4.) receive seventeen Pre-Pilot Questionnaires, and return envelopes. She also should receive cover letters as follows:

One letter with Dr. A's name (The intermediary adds one infant's name).
One letter with Dr. B's name (The intermediary adds one infant's name).
One letter with Dr. C's name (The intermediary adds two infant's names).
One letter with Dr. D's name (The intermediary adds one infant's name).
One letter with Dr. E's name (The intermediary adds one infant's name).
One letter with Dr. F's name (The intermediary adds one infant's name).

One letter with Dr. G's name (The intermediary adds two infant's name).
One letter with Dr. H's name (The intermediary adds two infant's name).
One letter with Dr. I's name (The intermediary adds one infant's name).
One letter with Dr. J's name (The intermediary adds one infant's name).
One letter with Dr. K's name (The intermediary adds one infant's name).
One letter with Dr. L's name (The intermediary adds three infant's name).

The intermediary then signs each letter (a total of 12 letters to 12 different primary care providers). (S)he then sends each letter with the correct number(s) of Pre-Pilot Questionnaires and return envelopes to the primary care provider(s). The completed questionnaires are then returned to the University of Washington Program Coordinator for analysis.

NOTE**: The state should not have any names of infants. The questionnaires should not have names of infants included. ONLY the cover letter completed by the intermediary should have the names of individual infants. The results should be reported in a manner such that individual infants or primary care providers cannot be identified.

HIGH PRIORITY INFANT TRACKING PROJECT

Pre-Pilot Study Questionnaire

Please complete the following questionnaire by indicating which answer best corresponds to information you have on the child named below.

INFANT'S BIRTHDATE: _____

PHYSICIAN/HEALTH CARE PROVIDER'S NAME (Optional): _____

Address: _____ City: _____ Zip: _____

---

1. HAVE YOU PROVIDED HEALTH CARE FOR THIS CHILD AFTER DISCHARGE FROM THE HOSPITAL FOLLOWING HIS/HER BIRTH (Check the appropriate response)?

   _____ YES IF "YES" Please answer questions #2 through #7.

   _____ NO IF "NO" Please skip questions #2 through #7 and answer only question #8.

2. How many times did you see this child during his/he first year of life for the following:

   - Immunizations only: _____ times
   - Well Child Care with or without immunizations _____ times
   - Illness Care Only: _____ times
   - Other (please Specify): _____ times

   _____

   _____

   _____

3. How many times did you see this child during his/her second year of life for the following:

   - Immunizations only: _____ times
   - Well Child Care with or without immunizations _____ times
   - Illness Care Only: _____ times
   - Other (please Specify): _____ times

_____

_____

_____

4. How would you rate this child's health?

   - Normal: _____

   - Abnormal (Please give reason): _____

_____

_____

_____

5. How would you rate this child's developmental status?

   - Normal: _____

   - Questionable: _____

   - Abnormal (Please give reason): _____

_____

_____

_____

6. Does this child and/or family utilize any other community/state services (i.e., public health nurse, referral to specialist clinic or physician, infant stimulation program, WIC, etc.)?

   _____ YES

   If YES, Please list services: _____

_____

_____

_____

   _____ NO

   _____ DO NOT KNOW

7. Is this child still obtaining care from you?

   _____ YES

If YES; you are now finished with the questions. Proceed to the end for further instructions.

_____ NO

If NO; please answer the following:

Please check the response most closely corresponding to the reason this child is not under your care:

_____ Moved out of County.

_____ Moved out of State.

_____ Moved to an unknown address.

_____ Referred to another health care provider.

_____ Deceased.

_____ Do Not Know.

_____ Other; Please specify reason: _____

_____

How old was this child when he/she stopped receiving care from you?

_____ months old.

---

8. (If you have not cared for this child since birth please answer just this question):

Please check the response most closely corresponding to the reason this child is ot under your care:

_____ Moved out of County.

_____ Moved out of State.

_____ Moved to an unknown address.

_____ Referred to another health care provider.

Name _____

_____ Deceased.

_____ Do Not Know.

_____ Other; Please specify reason: _____

_____

Thank you for your assistance with this pre-pilot study for the High Priority Infant Tracking Project. Your time and information is grealy appreciated.

Please return this questionnaire in the enclosed envelope.

(hospital)

Dear (physician)

Recently you received the data summary on the "High Priority Infant Tracking Project (HPIT)." As you may recall, the state Office of Maternal and Child Health Services, in coordination with the University of Washington, is currently conducting a pilot study of the "High Priority Infant Tracking Project" in both Whatcom and Thurston Counties. The pilot study in Thurston County began on May 1, 1984. You may now be participating in the tracking of several high priority infants through this system. To reiterate, the purposes of this program are as follows:

1. To assist parents keep their child under the care of a primary physician.

2. To promote early identification of infants requiring further evaluation or services.

3. To assist in planning for the health and educational needs of the children in Washington State.

In order to evaluate the effectiveness of the system in keeping infants in primary care, a determination of how many potentially high priority infants received ongoing primary care before the program began needs to be done. A similar pre-pilot study was done in Whatcom County, which indicated approximately 50 percent of potentially high priority infants were lost to follow-up with the infants' primary health care providers. Since beginning the pilot project in Whatcom County, greater than 96 percent of high priority infants enrolled into the tracking project have not been lost. Benefits of a tracking program will be more substantiated if similar results are found in Thurston County.

A random sample of charts of all infants admitted to (hospital) at or before 30 days of age from November 1, 1982 to April 30, 1983, were reviewed. Infants meeting one or more of the identifying criteria were identified. A list of the identifying criteria can be found on the attached Identification Form. Once identified as "potentially high priority," we need to determine if these infants have/are receiving ongoing health care. This information will then be compared to data obtained from infants enrolled into the tracking project from May 1, 1984 to May 1, 1986.

The infant(s) listed on the next page(s) were identified as "potentially high priority" during the chart review, and your name was listed as primary care provider. Could you review your records and determine whether or not each infant is "under care" or "not under care." Please complete the attached questionnaire to answer questions regarding each identified infant and return this questionnaire in the enclosed envelope by September 1, 1985, to the following address:

Patricia Biro, M.Ed., Coordinator
High Priority Infant Tracking Project
CDMRC - WJ 10
University of Washington
Seattle, WA 98195

Participation in this pilot study is voluntary. You are free to not answer any question you find objectionable. Your return of the completed questionnaire will imply your consent to use the questionnaire as data in this study. Your decision on whether or not to participate in this study will in no way affect existing benefits you receive from this hospital, the state Office of Maternal and Child Health Services, or the University of Washington. There will be no cost to you, nor will you be paid. The questionnaire should take less than ten minute to complete.

All information obtained from the questionnaires will be anonymous. Only people directly involved with the data analysis of the High Priority Tracking Program will have access to the questionnaires. The data will be kept in a secure location for a maximum of a five-year period.

Thank you for your interest and assistance. If any questions should arise, please feel free to contact Patricia Biro at (206) 543-1026.

Sincerely,

____(intermediary)____

___:men

Enclosures

PROGRAM EVALUATION

Evaluation Questionnaire Procedure

The following procedures were used to obtain information and feedback from participants in the High Priority Tracking Project in Whatcom and THurston Counties. Separate questionnaires were developed for the three target groups; community physicians, hospital and health department nursing staffing, and parents of infants enrolled in the project.

Step 1 A. Health care providers in both Whatcom and Thurston County were identified, and current addresses were verified with the telephone book, or by telephone.

B. Hospital and Health Department staff were identified and addresses were verified.

Step 2 A. A letter to health care providers was developed. (See examples on following pages.) This letter was designed to address physicians, nursing professionals and other health care providers.

Step 3 Questionnaires, cover letters, and pre-addressed, postage-paid envelopes for return to the University of Washington were mailed to the health care providers in each county. A careful record of the names, and numbers of questionnaires sent was kept.

Step 4 A cover letter to participating parents was developed for each county. This letter (see example) was sent to the parent with the accompanying questionnaire by the local health department High Priority Infant Tracking Project Coordinator.

Step 5 A. Parent questionnaires, cover letters, and preaddressed, postage paid envelopes for return to the University of Washington were mailed to the parents from each local health department.

B. This was done to ensure confidentiality. The names of the enrollees, and their parents are known to the local health department staff, but not to state, or university personnel.

Step 6 All questionnaires from parents, health care providers, hospital and health department staff were analyzed at the University of Wasnington.

Step 7 The results of the questionnaire are contained in the report "Program Evaluation: Evaluation Questionnaire."

SAMPLE LETTER #4
Evaluation Questionnaire Cover Letter

Date

Patricia Biro, Coordinator
High Priority Infant Tracking Project
CDMRC - WJ 10
University of Washington
Seattle, WA 98195

Dear Healtn Care Professional,

Tne state office of Maternal and Child Health Care Services in coordination with the University of Washington is conducting an evaluation of the High Priority Infant Tracking Project. The Project began in Whatcom County in October, 1982. Thurston County was added as a matched county in May, 1984. Over 400 high priority infants have been successfully identified and are in the tracking phase of the pilot project.

The objectives of the project are as follows:

1. To help parents keep their child under the care of their primary physician.

2. To promote early identification of infants requiring further evaluation or services.

3. To assist in planning for the health and educational needs of the children of our state.

As the pilot phase of the project draws to a close we are seeking feedback regarding the program from those professionals who have been directly involved in the High Priority Infant Tracking Project.

I hopethat you will take a few minutes to answer the questionnaire enclosed, and return to me in the stamped self addressed envelope. Your opinions and suggestions are important to the continuation and improvement of the project. Please return the questionnaire by _____.
date

All information obtained from the questionnaire will be anonymous. Only people directly involved with tne data analysis of the questionnaire will have access to tnis information. The data will be kept in a secure location for a maximum of five years.

Should questions arise please contact me at 543-1026. Thank you for your assistance and continued interest.

Sincerely,

Patricia Biro, Coordinator
High Priority Infant Tracking Project

Enclosures

SAMPLE LETTER #5
Evaluation Questionnaire Letter to Parents

Date

Local Health Dept.
Address

Dear Parent:

Our records indicate tnat you and your family have been enrolled in the Hign Priority Infant Tracking Project in our community.

Tne project began in Whatcom County in October 1982. Thurston County was added as a matched county in May 1984. Over 400 high priority infants have been successfully identified and are in the tracking phase of the pilot project.

The objectives of the project are as follows:

1. To help parents keep their child under the care of their physician.
2. To promote early identification of infants requiring further evaluation or services.
3. To help in planning for the health and educational needs of the children of our state.

We are hoping that you will take a few minutes from your busy schedule to complete tne enclosed questionnaire and return it in the pre-addressed envelope. Information from the questionnaire will help us to improve and expand tne HPIT Project to better meet the needs of our high priority infants and tneir families.

All information obtained from the questionnaire will be anonymous. Only people directly involved with tne data analysis of the questionnaire will have access to tnis information. Tne data will be kept in a secure location for a minimum of five years.

Your opinions are valuable to us. Please complete the questionnaire today. Tnank you for your help in evaluating this community project. Please return the questionnaire in the enclosed stamped envelope by DATE. If you have any questions regarding the questionnaire or the project, please feel free to contact me at (telephone).

Sincerely,

Local HPIT Coordinator

SAMPLE QUESTIONNAIRE #1

HIGH PRIORITY INFANT TRACKING PROJECT

(HPIT)

PHYSICIAN EVALUATION QUESTIONNAIRE

PLEASE COMPLETE THE FOLLOWING QUESTIONNAIRE BY CIRCLING THE NUMBER WHICH BEST CORRESPONDS TO YOUR OPINION OF THE HIGH PRIORITY INFANT TRACKING PROJECT (HPIT).

	STRONGLY DISAGREE						STRONGLY AGREE
1. In general the HPIT Project is a valuable community service.	1	2	3	4	5	6	7
2. The HPIT Project is an efficient way of assuring follow-up of nigh priority infants.	1	2	3	4	5	6	7
3. The HPIT Project helps estimate the occurence of disabilities in children.	1	2	3	4	5	6	7
4. I use the HPIT Project to help identify infants with health and/or developmental problems.	1	2	3	4	5	6	7
5. The HPIT Project has assisted me in providing appropriate evaluation, intervention, and/or support services as early as possible.	1	2	3	4	5	6	7
6. The Identification Form takes too much time to complete.	1	2	3	4	5	6	7
7. The Tracking Form takes too much time to complete.	1	2	3	4	5	6	7
8. This project can only be continued with state financial support.	1	2	3	4	5	6	7

	STRONGLY DISAGREE						STRONGLY AGREE
9. The present tracking schedule of tnree, six, twelve, eighteen, 24 and 36 months is appropriate.	1	2	3	4	5	6	7
10. The identification of high priority infants has NOT caused parents unnecessary worry.	1	2	3	4	5	6	7
11. High Priority Infant Tracking is adequate WITHOUT a state-wide organized program.	1	2	3	4	5	6	7
12. I would like to continue participation in the HPIT Project.	1	2	3	4	5	6	7

13. Infants enrolled in the HPIT Project receive the (_____) same, (_____) better, or (_____) worse, follow-up as did high priority infants identified before the HPIT Project was implemented.

14. I would like to see the following changes in the HIGH PRIORITY INFANT TRACKING PROJECT:

THANK YOU FOR YOUR CONTINUED INTEREST AND ASSISTANCE WITH THE HIGH PRIORITY INFANT TRACKING PROJECT. PLEASE RETURN YOUR QUESTIONNAIRE IN THE ENCLOSED ENVELOPE.

revised 1/86

SAMPLE QUESTIONNAIRE #2

HIGH PRIORITY INFANT TRACKING PROJECT

(HPIT)

HOSPITAL/HEALTH DEPARTURES EVALUATION QUESTIONNAIRE

PLEASE COMPLETE THE FOLLOWING QUESTIONNAIRE BY CIRCLING THE NUMBER WHICH BEST CORRESPONDS TO YOUR OPINION OF THE HIGH PRIORITY INFANT TRACKING PROJECT (HPIT).

	STRONGLY DISAGREE						STRONGLY AGREE
1. In general, the HPIT Project is a valuable community service.	1	2	3	4	5	6	7
2. The HPIT Project is an efficient way of assuring follow-up of high priority infants.	1	2	3	4	5	6	7
3. The HPIT Project helps estimate the occurrence of disabilities in children.	1	2	3	4	5	6	7
4. I use the HPIT Project to help identify infants with health and/or developmental problems.	1	2	3	4	5	6	7
5. The HPIT Project brochure adequately explains the HPIT Project to parents.	1	2	3	4	5	6	7
6. The Identification Form takes too much time to complete.	1	2	3	4	5	6	7
7. This project can only be continued with state financial support.	1	2	3	4	5	6	7
8. Tracking of High Priority Infants is adequate WITHOUT a state-wide organized program	1	2	3	4	5	6	7

	STRONGLY DISAGREE						STRONGLY AGREE
9. Participation in the HPIT Project has improved my ability to recognize biological and environmental risk factors.	1	2	3	4	5	6	7
10. The present tracking schedule of three, six, twelve, eighteen, 24 and 36 months is appropriate.	1	2	3	4	5	6	7
11. I would like to continue participation in the HPIT Project.	1	2	3	4	5	6	7

12. Infants enrolled in the HPIT Project receive the (_____) same, (_____) better, or (_____) worse follow-up as did high priority infants identified before the project was implemented.

HEALTH DEPARTMENT PERSONNEL: Please answer Question #13, #14, and #15. Otherwise go to Question #16.

13. It takes too much time to send out tracking forms to the appropriate physicians.	1	2	3	4	5	6	7
14. It takes too much time to follow up on High Priority infants once lost by their private physician.	1	2	3	4	5	6	7
15. The benefits of the HPIT Project are worth the time required.	1	2	3	4	5	6	7

16. I would like to see the following changes in the HIGH PRIORITY INFANT TRACKING PROJECT:

THANK YOU FOR YOUR CONTINUED INTEREST AND ASSISTANCE WITH THE HIGH PRIORITY INFANT TRACKING PROJECT. Please return your questionnaire in the enclosed envelope.

SAMPLE QUESTIONNAIRE #3

HIGH PRIORITY INFANT TRACKING PROJECT

(HPIT)

PARENT EVALUATION QUESTIONNAIRE

PLEASE COMPLETE THE FOLLOWING QUESTIONNAIRE BY CIRCLING THE NUMBER WHICH BEST INDICATES YOUR OPINION OF THE HIGH PRIORITY INFANT TRACKING PROJECT (HPIT).

	STRONGLY DISAGREE						STRONGLY AGREE
1. I believe the High Priority Infant Tracking Project helped maintain regular check-ups and care for my child with his/her physician.	1	2	3	4	5	6	7
2. I believe the High Priority Infant Tracking Project helps to assure my child receives needed community services (e.g., public health nurse, referral to a specialist, infant stimulation programs, physical therapy, etc.).	1	2	3	4	5	6	7
3. I feel the High Priority Infant Tracking Project is a valuable service to my community.	1	2	3	4	5	6	7
4. The High Priority Infant Tracking Project Parent Brochure explained the project well.	1	2	3	4	5	6	7
5. The hospital staff explained the High Priority Infant Tracking Project to me in a way I could understand.	1	2	3	4	5	6	7
6. I became unnecessarily worried about my child's health due to being enrolled in the High Priority Infant Tracking Project.	1	2	3	4	5	6	7

	STRONGLY DISAGREE						STRONGLY AGREE
7. I believe state involvement in organizing a tracking program for high priority infants is beneficial.	1	2	3	4	5	6	7
8. I feel my privacy has been invaded by having my infant enrolled in the High Priority Infant Tracking Project.	1	2	3	4	5	6	7
9. I felt my infant was appropriately identified as "nigh priority."	1	2	3	4	5	6	7
10. I feel that participation in the High Prioroity Infant Tracking Project is a service that should be available for all high priority infants and their families.	1	2	3	4	5	6	7
11. I feel that the health care of my family has improved as a result of the High Priority Infant Tracking Project.	1	2	3	4	5	6	7
12. I feel that my pnysician provides my infant with better care as a result of our participation in the High Priority Infant Tracking Project.	1	2	3	4	5	6	7

COMMENTS:

THANK YOU FOR YOUR ASSISTANCE IN EVALUATING THE HIGH PRIORITY INFANT TRACKING PROJECT. Please return your completed questionnaire in the enclosed envelope.

PROGRAM EVALUATION

COST ANALYSIS

A cost analysis can help to provide an evaluation of the cost of a project in terms of human and fiscal resources. Each county implementing the HPIT Project may utilize their resources in differing ways, depending on their own community needs, and priorities. A cost analysis was completed for the Fiscal Year: July 1, 1984 to June 30, 1985. The findings were reported in the report: High Priority Infant Tracking Project: Cost Analysis Report. A review of this document may help to identify the types of resources necessary in the implementation of the HPIT Project. It should be remembered that the costs reported in the document are estimates, and reflect expenses involved in a PILOT PROJECT, rather than an established project.

SECTION VI

PROJECT ACTIVITIES SCHEDULE

A. Weekly Activities. 61

B. Monthly Activities 62

C. Quarterly Activities 63

D. Bi-annual Activities 64

E. Annual Activities. 65

PROJECT ACTIVITIES SCHEDULE

ACTIVITIES TIMELINE

The following activities have been recommended by the HPIT Project participants. They represent an ongoing activities schedule during the IMPLEMENTATION PHASE of the HPIT Project.

WEEKLY ACTIVITIES

Hospitals/Identification Sites

1. Identify eligible infants for HPIT Project.
2. Maintain log of infants identified.

Local Health Department/Coordinating Agency

1. Collect IDENTIFICATION FORMS from the hospitals.
2. Set up new Tickler Cards/Files for the new cases identified.
3. Process TRACKING FORMS received from physician's or health clinics.
4. Review new IDENTIFICATION FORMS, and TRACKING FORMS for potential follow-up.

Physician's Office/Health Clinic

1. Review case charts as TRACKING FORMS arrive.
2. Note any changes of access on the Tracking Form.
3. Complete TRACKING FORMS after the patient has been seen.
4. Return completed TRACKING FORMS to the local health department.

MONTHLY ACTIVITIES

Hospital/Identification Sites

1. Tabulate the number of HPIT infants for the month.

Local Health Department/Coordinating Agency

1. Mail the TRACKING FORMS to the physician's or health clinics, as indicated from the TICKLER CARD.

2. Mail the appropriate copies of the IDENTIFICATION FORM, and the TRACKING FORM to the University of Washington for data analysis.

3. Update the log of HPIT enrollees in the local health department.

4. Follow up on tracking forms not returned by the primary care provider.

5. Contact families who have not been seen by their primary care provider.

QUARTERLY ACTIVITIES

Local Health Department/Coordinating Agency

1. Provide inservice for hospital staff if needed.

2. Provide feedback to hospital staff, health clinics, and physician's regarding the progress of the project.

3. Hospitals or identification sites which are a great distance away from the local health department/coordinating agency are contacted by telephone. (For example, the regional NICU contact may be phoned quarterly.)

Hospitals/Identification Sites

1. Meet with the local HPIT coordinator to review the progress of the project and troubleshoot potential problem areas. This may be an informal breakfast or luncheon meeting.

SEMI-ANNUAL ACTIVITIES

Local Advisory Board

1. Hold a meeting for the general membership and invited guests to review the progress of the project and provide guidance for the next six month period.

Hospitals/Identification Sites

1. Hold a brief meeting to update staff on the progress of the project and to ensure ongoing enrollment of appropriate infants.

   Staff members should be invited from the Nursery, Post Partum, Labor and Delivery, and Pediatrics Departments.

Local Health Department/Coordinating Agency

1. Arrange and conduct chart review activities in cooperation with the hospitals and identification sites.

2. Meet with administrative and supervisory staff from the State Office of Maternal-Child Health and the University of Washington.

Physician's offices/Health Clinics

1. Provide feedback to the local health department HPIT Coordinator regarding the project, and give suggestions on how to improve the project.

2. Local pediatricians, family practice physicians may want an update on the project at a medical society or other professional meeting. This is an important means of information exchange between program coordinator and private providers.

ANNUAL ACTIVITIES

LOCAL HEALTH DEPARTMENT/COORDINATING AGENCIES

1. Address the local County Commissioners and/or the County Board of Health to provide information and feedback on the progress of the project.

2. Review project progress for the past year, and develop annual objectives for the next project year.

3. In coordination with the hospital HPIT liaison arrange a meeting with the hospital administration to discuss the project, and assess the hospital's participation/contribution to the project.

Hospitals/Identification Sites

1. Review information from the chart review process, case log, and staff input with the local health department HPIT Coordinator.

2. Help to develop suggestions for program improvement, sharing data, and developing yearly objectives.

SECTION VII

APPENDICES

A. Definitions

B. Parenting/Social/Environmental Risk Factors

C. IDENTIFICATION FORM

D. TRACKING FORM

E. CHART REVIEW FORM

APPENDIX A

Definitions

DEFINITIONS: The following definitions are provided to clarify the use of terminology used in the PROCEDURES MANUAL.

AT RISK: An infant is presumed to be "at risk" for poor medical; developmental and/or educational outcomes as a result of negative biological and/or environmental factors.

BIOLOGICAL RISK: This category refers to infants and children who present a history of prenatal, perinatal, neonatal, and early developmental events suggestive of biological insult(s) to the developing central nervous system, such as prematurity, abnormalities of tone, delay in achieving gross or fine motor milestones, abnormal neurological exams, unusual behaviors, feeding difficulties, etc.

ESTABLISHED RISK: This category refers to infants or children at known risk of abnormal health or developmental outcome due to a diagnosed condition such as chromosomal abnormality, chronic illness or physical disability. this can usually be diagnosed in the perinatal period.

DOUBLY VULNERABLE: This condition exists when an infant or child presents both biological and environmental risk factors.

ENVIRONMENTAL RISK: This category refers to infants and children who present the potential for delayed development because of limiting early environmental experiences, limited financial resources, or family situations, such as parental age, parental stress, developmental disability in one or both parents, maternal or paternal substance abuse or dependance, known history of child abuse or neglect, etc.

HIGH PRIORITY: This term is used to designate infants and children who present biological and/or environmental risk factors, and are eligible for the Washington State High Priority Infant Tracking Project.

IDENTIFICATION: This is the process of establishing program eligibility, and entering infants into the tracking system. Activities included in identification are: screening, or flagging infants who are potential HPIT infants, evaluation of eligibility criteria, and formal entry into the program; including obtaining parental and physician consent.

PARENTING RISK: These are risk factors due to parental behavior or history, as parenting risk is a subset of Environmental Risk.

Definitions

TRACKING: Tnis is the process of organized follow-up for infants who are "at risk." This results in identification of vulnerable infants, enabling prompt evaluation and/or treatment to minimize deficits and promote optimum functioning.

*Definitions were adapted from the Project 0-3 Survey Report 1. National Center for Clinical Infant Programs, 1985.

APPENDIX B

ENVIRONMENTAL, SOCIAL, PARENTING RISK FACTORS

Infants who are "at risk" for biological and/or established risk conditions are often easy to identify at an early age.

Infants who are "at risk" due to social/environmental or parenting risks are more difficult to objectively identify and document as being in need of resources/services.

These definitions are taken from the Pocket Guide to Nursing Diagnoses, Kim, M.S., McFarland, G.J., and McCane, A.M., C.V. Mosby Company, St. Louis, 1984.

ENVIRONMENTAL/SOCIAL RISKS

* KEY POINTS

1. An infant's environment is his home.

2. It is a "best practice" for all infants to have a safe, growth promoting home.

IMPAIRED HOME MAINTENANCE

Definition: The parent is unable to independently maintain a safe, growth promoting immediate environment.

Etiology:

Disease or injury of a family member

Insufficient family organization or planning

Insufficient finances

Unfamiliarity with neignborhood resources

Impaired congitive or emotional functioning

Lack of knowledge

Lack of role modeling

Inadequate support systems

Defining Cnaracteristics:

Subjective:

Family members report outstanding debts or financial crises

Family members request assistance in home maintenance

Family members express difficulty in home maintenance

Objective:

Disorderly surroundings (document in writing)

unwashed or unavailable cooking equipment, clothes, linen, or lack of appropriate infant supplies/furniture

Accumulation of dirt, food waste, or other waste problems.

Offensive odors

Inappropriate household temperature

Overtaxed (exhausted) family members

Lack of necessary equipment or aids

Presence of vermin or rodents

Repeated hygienic disorders, infestations, or infections

* KEY POINTS

1. Infants are dependent on their parents.

2. Most parents experience a period of adjustment to parenthood. This is NORMAL.

Actual or Potential for an Alteration of Parenting

Definition: an alteration in the ability of a nurturing individual to provide an environment that promotes optimum growth and development of another human being.

Etiology:

Lack of role models

Physical and psychosocial abuse of nurturing figure

Lack of support between or from significant other(s)

Unmet social and emotional maturation needs of parenting figures

Interruption in the bonding process (e.g., maternal, paternal, other)

Perceived tnreat to own survival: physical and emotional

Mental and/or physical illness

Presence of stress: financial or legal problems, recent crisis, cultural move

Lack of knowledge

Limited cognitive functioning

Lack of role identity

Lack of appropriate response of child to relationship

Multiple pregnancies which tax tne family's resources

Unrealistic expectations for self, infant, partner

Defining characteristics:

Actual and potential

Lack of parental attachment behaviors: examples

inappropriate visual, tactile, auditory stimulation

negative identification of characteristics of infant/child

Constant verbalization or disappointment in gender or physical characteristics of infant/child

Verbalization of resentment toward the infant/child

Verbalization of role inadequacy

Inattention to infant/child needs

Verbal disgust at body functions of infant/child

Non-compliance with health appointments for self and/or infant/child (therapy? educational services?)

** Inappropriate caretaking behaviors (toilet training, feeding, sleep and rest, etc.)

Inappropriate or inconsistent discipline practices

Frequent accidents

Frequent illness

Growth and Development lag in the child

* History of child abuse by primary caretaker

* Child receives care from multiple caretakers without regard to the needs of the child.

Actual:

Abandonment

Runaway

Verbalizes cannot control the child

Evidence of physical and psychological trauma

HIGH PRIORITY INFANT IDENTIFICATION FORM OF WASHINGTON STATE CASE NUMBER _____

PATIENT DATA

CHILD'S NAME _____ (last) (first) (middle)

DATE OF BIRTH _____ GESTATION (weeks) _____ ( ) Male ( ) Female

Infant born in this hospital ( ) Yes ( ) No If no, hospital of birth _____

MOTHER'S NAME _____ (last) (first) (middle)

FATHER'S NAME _____ (last) (first) (middle)

GUARDIAN, if any _____ (last) (first) (relationship)

ADDRESS _____ (street or route no.) (town) TELEPHONE _____

_____ (county) (zip)

Name of persons other than parents who will know where child can be located:

1. _____ (name) (address) (telephone no.)

2. _____ (name) (address) (telephone no.)

HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)

( ) Birth weight ≤5 lbs. 8 oz (≤2500 gms.) BIRTH WEIGHT _____ gms
( ) Birth weight ≤10th %tile for gestational age (SGA) ____ lb. ____ oz
( ) Head Circumference (OFC) ≤10th %tile or ≥90th %tile for gestational age OFC ____ in./cms
( ) Apgar score less than 4 at 5 minutes APGAR _____
( ) Intracranial hemorrhage
( ) Seizures
( ) Clinical impression of neurological abnormality DESCRIBE _____
( ) Acquired CNS infection (e.g., meningitis) DESCRIBE _____
( ) Hyperbilirubinemia (≥20 mg-%) mg-% _____
( ) Suspected/confirmed hearing impairment
( ) Suspected confirmed visual impairment
( ) Major birth defect or syndrome DESCRIBE _____
( ) Congenital fetal infection ( ) toxoplasmosis ( ) rubella ( ) herpes ( ) cytomegalic virus ( ) syphilis
( ) Confirmed congenital hypothyroidism
( ) Confirmed PKU
( ) Mother 15 years of age or under AGE ____ yrs
( ) Significant environmental, social, or parenting risk DESCRIBE _____
( ) Other problems _____

FORM COMPLETED BY _____ DATE _____

I have reviewed the above information and believe it to be correct.

_____ DATE _____
(Attending Physician Signature)

PARENT'S PERMISSION

I have had the High Priority Infant Tracking Program explained to me orally and in writing and agree to having my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information as indicated above to my child's health care provider and to the local health department where my child resides presently or in the future. I understand I can withdraw my child from this program at any time. My child's health provider is:

_____ (name of health provider)

_____ (address) (town) (state) (zip)

_____ (Witness Signature) (Parent's Signature)

_____ (Date) (Date)

( ) Refused tracking system _____

TIME RECORD FOR THIS PATIENT

HOSPITAL STAFF

TIME SPENT ON HPIT: Please check appropriate time spent in each activity.

IDENTIFICATION (eg. identifying infant; preparing forms and charts, etc.)
( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

PARENT CONTACT (eg. obtaining consent; explaining program, etc.)
( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

HEALTH DISCIPLINE CONTACTS (eg. communication with other staff relative to HPIT activities)
( ) None ( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

FORM SENT TO: _____ CASE NUMBER _____

HIGH PRIORITY INFANT TRACKING FORM OF WASHINGTON STATE

PATIENT DATA

CHILD'S NAME: _____ DATE OF BIRTH _____

PARENT'S NAME: _____ TELEPHONE: _____

ADDRESS: _____

(street or route number) (town) (county) (zip)

If different from above, please correct: _____

RETURN FORM TO

AGENCY: _____ ATTENTION: _____
(person requesting information)

ADDRESS: _____ TELEPHONE: _____

Check TRACKING CONTACT.( )3-4 mos.( )6-7 mos.( )12 mos.( )18 mos.( )24 mos.( )30 mos.( )36 mos.

TRACKING DATA

Is this child still receiving health care from you? ( ) Yes ( ) No

If no, indicate reason: ( ) Don't know ( ) Cannot locate ( ) Deceased

( ) Moved to: _____ (state or county)

( ) Referred to another physician: _____

Address: _____

( ) Other: _____

Please indicate:

I. HEALTH STATUS: ( ) Normal ( ) Other. If other, check **MAJOR** problems and specify as necessary below.

( ) A. CNS. ( ) Cerebral Palsy ( ) Seizures ( ) Hydrocephalus

( ) Structural defects, specify: _____

( ) Other: _____

( ) B. Pulmonary, specify: _____

( ) C. Cardiac, specify: _____

( ) D. Renal, specify: _____

( ) E. GI, specify: _____

( ) F. Growth Disorders: ( ) Failure to thrive

( ) Head Circumference (≤3rd %tile or ≥97th %tile)

( ) G. Malformation or syndromes, specify: _____

( ) H. Sociomedical: ( ) Child abuse/neglect ( ) Other, specify: _____

( ) I. Other, specify: _____

II. BEHAVORIAL/SENSORY DEVELOPMENT

A. Developmental Milestones — considering age (corrected for prematurity if any)

1. Personal-social:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
2. Fine motor:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
3. Gross motor:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
4. Language:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
5. Mental:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment

B. Vision: ( ) Normal ( ) Abnormal, specify _____

C. Hearing: ( ) Normal ( ) Abnormal, specify _____

D. Other, specify: _____

III. INTERVENTION SERVICES

A. With respect to the problems mentioned above, has the child and family received services from other community agencies during the past year?

( ) No ( ) Yes. If yes, specify type: _____

B. If no, why is the child not receiving these services? ( ) managing problems myself

( ) family refused ( ) appropriate services not available in community

Date last seen by you _____

TIME RECORD

FOR PRIMARY HEALTH CARE PROVIDER ONLY: Please check appropriate box indicating time spent in completing form.

( ) 1-5 min. ( ) 6-11 min ( ) 12-17 min. ( ) 18-23 min ( ) 24-29 min ( ) 30-35 min

( ) Other, please specify in minutes _____

CASE CLOSURE

FOR PHN ONLY.

Date of closure: _____ Reason Moved out of ( ) state or ( ) county

( ) Parental permission withdrawn

( ) Cannot locate ( ) Deceased

TIME RECORD FOR THIS PATIENT

Time spent on HPIT: Please check appropriate time spent in activity

ADMINISTRATION (eg. developing file, sending tracking form, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

PARENT CONTACT (eg. activities related to tracking lost infant, follow-up, etc.)

( ) none ( ) 1-20 min. ( ) 31-60 min. ( ) 61-120 min. ( ) 2-3 hrs. ( ) 3-4 hrs.

( ) Other, please specify in hours _____

PRIMARY HEALTH CARE PROVIDER CONTACT (eg. communication relative to HPIT activities)

( ) none ( ) 1-10 min. ( ) 11-20 min. ( ) 21-31 min. ( ) 32-42 min. ( ) 43-53 min.

( ) 54-64 min. ( ) Other, please specify in hrs. _____

COPY TO: WHITE — HEALTH DEPARTMENT CANARY — HPIT PROJECT

HIGH PRIORITY INFANT TRACKING PROJECT CHART REVIEW INFORMATION

_____ case number

_____ date of birth _____ gestational age (weeks)

_____ sex infant born in this hospital?_____

if no, hospital of birth _____

_____

Inclusion criteria:

HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)

( ) Birth weight ≤5 lbs 8 oz (≤2500 gms) BIRTH WEIGHT _____ gms
( ) Birth weight ≤10th %tile for gestational age (SGA) ___ lb. ___ oz.
( ) Head Circumference (OFC) ≤10th %tile or ≥90th %tile for gestational age OFC ___ in. cms
( ) Apgar score less than 4 at 5 minutes APGAR ___
( ) Intracranial hemorrhage
( ) Seizures
( ) Clinical impression of neurological abnormality DESCRIBE _____
( ) Acquired CNS infection (e.g., meningitis) DESCRIBE _____
( ) Hyperbilirubinemia (≥20 mg%) mg% ___
( ) Suspected confirmed hearing impairment
( ) Suspected confirmed visual impairment
( ) Major birth defect or syndrome DESCRIBE _____
( ) Congenital fetal infection: ( ) toxoplasmosis ( ) rubella ( ) herpes ( ) cytomegalic virus ( ) syphilis
( ) Confirmed congenital hypothyroidism
( ) Confirmed PKU
( ) Mother 15 years of age or under AGE ___ yrs
( ) Significant environmental, social, or parenting risk DESCRIBE _____
( ) Other problems: _____

Comments:

_____

Time spent on chart review: _____